

Statewide 5-Year Maternal and Child Health Needs Assessment Alabama Fiscal Year 2009-10

Focus on Children and Youth with Special Health Care Needs

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The following document has been edited from the actual submission to the Maternal and Child Health Bureau. It is a compilation of findings for children and youth with special health care needs (CYSHCN) as prepared by Children's Rehabilitation Service (CRS). The actual submission from Alabama results from a collaborative process with the Alabama Department of Public Health and covers all Title V populations (women, infants, children and youth, including children and youth with special health care needs). The material presented is not intended to stand alone, but rather to highlight findings specific to children and youth with special health care needs. The full submission is available upon request through the Alabama Department of Public Health and will be available on the Maternal and Child Health Bureau website (www.mchb.hrsa.gov) mid-fall of 2010. For any additional questions about the CYSHCN portion of the Alabama Needs Assessment, please contact Children's Rehabilitation Service, Julie Preskitt, at (334) 293-7165 or 1-800-441-7607.

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SECTION 1

PROCESS FOR CONDUCTING NEEDS ASSESSMENT

Overall Methodology and Partnerships

Alabama's Maternal and Child Health Program

Children and Youth with Special Health Care Needs

In Alabama, the Title V Maternal and Child Health Program is administered by the Alabama Department of Public Health, through the division of Family Health Services. Family Health does not directly administer Alabama's programs focusing on children and youth with special health care needs (CYSHCN), but contracts with Children's Rehabilitation Service (CRS), a division of the Alabama Department of Rehabilitation Services, to administer services to this population. Given this relationship and organizational model, CRS staff perform the needs assessment for Alabama's CYSHCN. Therefore, the Alabama Department of Rehabilitation Services (ADRS), through the division of CRS, was the lead agency for the assessment of CYSHCN. Needs Assessment Coordinators for Family Health Services and CRS collaborate with one another, and representatives from both agencies participate as part of the other organization's needs assessment advisory group. The State Parent Consultant and a Local Parent Consultant for CRS were members of both advisory groups.

The Needs Assessment Coordinators for Family Health Services and CRS collaborated in the preparation of the final needs assessment report. Specifically, CRS's Needs Assessment Coordinator provided material pertaining to that organization's components of the needs assessment to Family Health Services' Needs Assessment Coordinator, who integrated all materials into Alabama's final needs assessment report to be submitted to the federal government. The two coordinators collaborated with one another if any content-related issues arose as material was being integrated.

Establishment of the Children's Rehabilitation Service Needs Assessment Advisory Committee

The CRS Needs Assessment Advisory Committee was developed based on ongoing partnerships with key stakeholders, including youth with special health care needs (YSHCN) and families of CYSHCN. CRS convened a Needs Assessment Advisory Committee, which met two times during 2009 to assist CRS in planning and implementing the CYSHCN portion of the State's FY 2009-10 MCH needs assessment, as well as with analyzing and prioritizing the results. Updates were also sent to the committee members at strategic points during the process. CRS pursued three distinct methodologies, described under "Quantitative and Qualitative Methods."

Quantitative and Qualitative Methods

Methods and Sources: CYSHCN and Capacity

Planning for the CYSHCN portions of the needs assessment began in the summer of 2008. The department entered into agreements with Family Voices of Alabama (FVA) and the School of Public Health at the University of Alabama at Birmingham (UAB) to assist with the process. A small leadership team – including the CYSHCN Director, the coordinator of the CYSHCN portions of the needs assessment, the CRS State Parent Consultant/Family Voices of Alabama Co-coordinator, a CRS Local Parent Consultant, the CRS Audiology Program Specialist (who has a particular interest in maternal and

child health), and a professor from the UAB School of Public Health – directed these early planning efforts.

As previously stated, CRS convened a Needs Assessment Advisory Committee, which met two times during 2009 (February and December) to assist the agency in planning and implementing the CYSHCN portion of the Alabama needs assessment, as well as with analyzing and prioritizing the results. Updates were also sent to the committee members at strategic points during the process. Members included representatives from other State agencies and providers critical to the system of care for CYSHCN, CRS administrative staff, members of the CRS Youth Advisory Committee, and parents of CYSHCN. The total membership of the Committee was 65, with about half of those attending the in-person meetings. With the input and varied expertise of the various stakeholders in the group, CRS analyzed existing secondary data and gathered quantitative and qualitative data to determine the priority needs of Alabama's CYSHCN. Secondary data were obtained from federal, state, and local sources and included analysis of Alabama results from the National Survey of Children and Youth with Special Health Care Needs, 2005-2006 and the National Survey of Children's Health, 2007. Primary data were collected using three distinct methodologies:

- **Focus Groups:** Qualitative and quantitative data were gathered from the family, youth, and key State-level stakeholders' perspective through a series of focus groups held throughout the State at varying times and days of the week to accommodate family and youth schedules. Four family focus groups were conducted July through September 2009 at sites throughout the State. Focus groups were located in Huntsville, Birmingham, Tuscaloosa, and Jackson. One of the four groups (Birmingham) was conducted in Spanish. The youth focus group was held in June in Montgomery. The focus group for key State-level stakeholders was held in September, also in Montgomery. All sites were accessible public facilities, such as community meeting centers, churches, libraries, and local business establishments. The focus groups were hosted by FVA, which also provided refreshments, reimbursements for transportation and child care, and an advisory honorarium for participants. The logistics of the focus group, recruitment of participants, and facilitation of the sessions were coordinated through the MCH Department of UAB School of Public Health. A professor conducted the focus groups for English-speaking families and those for key State-level stakeholders and youth, while a doctoral student in the program facilitated the session for Spanish-speaking families. The UAB facilitators compiled a written summary report of findings from the family and youth perspective, including information from the focus groups and surveys (see next section). CRS held open family forums as a part of the 1999 MCH needs assessment methodology and added a youth forum and a forum conducted in Spanish language for the 2004 cycle. A session for key State-level stakeholders was newly added in 2009, as well as a shift to more formal focus groups instead of open forums. This shift allowed recruiting efforts to assure broader representation across socioeconomic, geographic, and disability-type variables as well as reaching out to families and youth not enrolled in CRS.
- **Surveys:** Qualitative and quantitative data were gathered from the perspective of families of CYSHCN, youth with special health care needs (YSHCN), and county-level providers of care for CYSHCN through three separate surveys. The surveys for providers and for youth were modified from survey tools used in previous MCH needs assessments (providers in 1994, 1999, and 2004; youth in 2004) to facilitate analysis and comparison over time. The survey for families was a new methodology. A fourth survey – targeting medical and allied health providers for CYSHCN across the system of care in the State – was originally planned. However, many of those potential target providers participated in county-level provider surveys through their contacts with local CRS offices. This local connection increased the response to the county-level provider surveys, in part due to the established working relationships developed by local CRS staff. It did, however, tap into the target population for the planned fourth survey, envisioned to be a broader assessment of system-of-care issues from the perspective of this population. This significant overlap led the smaller

leadership team to conclude that this fourth survey should be abandoned. In hindsight, had CRS planned to collapse these two surveys, the agency would continue to have outreach efforts be coordinated at the local level given the established relationships, but the following adjustments would have been made: 1) the county-level survey tool would have been modified to include broader system-of-care issues in addition to its current content 2) the methodology would have been expanded to allow electronic participation, and 3) all surveys would have been counted separately instead of collating into a response for the county.

- Family Survey- The family survey was adapted based on research of tools utilized in other settings and mirrored questions from the county-level provider survey and the National Survey of Children with Special Health Care Needs, 2005/06. The tool was piloted by CRS Local Parent Consultants and two to three Local Parent Advisory Committee members in each district. Modifications were made to the instrument based on feedback from the pilot group. Surveys were conducted May – September 2009. This survey was available via paper copy or electronic link using SurveyMonkey and was presented both in English and Spanish versions. Outreach was done using established listserv groups, a Facebook group, email, links on partner websites, columns in newsletters, paper copies in the 15 CRS community-based offices and other locations frequented by families of CYSHCN, and postcards. Data gathered through the family surveys included basic demographics and information on the need for, receipt of, and satisfaction with health and community-based services; on perceived barriers to care; on medical home; on transition services; and on informational needs. There was a large amount of missing data for certain questions; however, lack of resources prevented follow-up with respondents to clarify skipped questions and/or inconsistent responses. There were 1,103 surveys submitted, combining English and Spanish responses and both electronic and paper copy submissions. A response rate of 39.3 percent was calculated from the hard copy results, though this is likely an underestimate as a partner agency printed additional surveys to use with their activities and CRS was unable to determine how many of these were unused. There were responses from at least one family living in all of Alabama's 67 counties. Results will be considered as a baseline for the next needs assessment cycle and any interim updates.
- Youth Survey- The youth survey, first fielded in 2004, was adapted from a tool created by the North Carolina Title V Program as a part of their 1999 needs assessment process. The tool was modified for use in Alabama during 2004 and then again for 2009. The target population for 2009 was YSHCN ages 12-25 years. Surveys were conducted May – September 2009. This survey was available via paper copy or electronic link using SurveyMonkey and was presented both in English and Spanish versions. The 2004 youth survey was available in paper, English version only. Outreach was done using established listserv groups, a Facebook group, email, links on partner websites, columns in newsletters, paper copies in the 15 CRS community-based offices and other locations frequented by YSHCN, and postcards. Data gathered through the youth surveys included basic demographics and information on health and receipt of health care, transition, activities, future plans, and informational needs. There were 336 surveys submitted, combining English and Spanish responses and both electronic and paper copy submissions (up from 229 in 2004). A response rate of 37.2 percent was calculated from the hard copy results. There were responses from YSHCN living in 57 of Alabama's 67 counties. Results were compared with the information obtained from the 2004 survey.
- County-level Provider Survey- The provider survey was first fielded in 1994 as a county assessment tool used in the State Systems Development Initiative needs assessment (conducted by UAB School of Public Health). This tool was used in the 1999, 2004, and

2009 MCH needs assessment cycles with modifications to better match the system of care for CYSHCN at those times. Data gathered through the provider surveys included information on the availability of health and community-based services within the county or in an adjoining county and on perceived barriers to care. The availability information assisted CRS in assessing the State's capacity to provide direct, enabling, population-based, and infrastructure-building services. Surveys were conducted April – July 2009. CRS staff facilitated completion of the surveys through meetings with partner agencies in the counties, phone calls, faxed or emailed surveys to local contacts, and other solicited input. This broad directive for survey completion methodology allowed offices to manage this task in a way that best fit the local area; however, it also created some issues in counting respondents by county and in tallying information. There were 501 respondents counted across all counties, with results collated and/or averaged by CRS local staff to form one entry for the county. Commonly cited participants included representatives from the Alabama departments of Public Health, Human Resources, and Mental Health, as well as Alabama's Early Intervention System, local boards of education, and the juvenile justice system. Provider types included special education teachers, school nurses, probate judges, physicians, dentists, social workers, nurses, nutritionists, physical therapists, occupational therapists, and speech therapists. This survey was available via paper copy only (a PDF of the survey was available for electronic mailing to participants who requested to download the survey and fax it back to local offices). Follow-up was conducted with CRS local staff for clarification and to address missing information. The responses were stored in an Access database and results were analyzed using both Access and Excel software. Results were compared with the information obtained from the 1994, 1999, and 2004 surveys.

- **Key Informant Interviews:** Quantitative and qualitative data were also gathered from the perspective of key informants for each county. Following analysis of the county-level provider survey, CRS determined that gaps existed in the data and that additional clarification would be helpful in determining priority needs. To that end, a three-question interview was developed with input from UAB School of Public Health. Data gathered included assessments of the level of burden or difficulty faced by families living in the county in obtaining health and community-based services, the effectiveness of the overall system of care for CYSHCN and families in the county, and the three greatest service needs in the county. CRS District Supervisors and Office Coordinators were selected as key informants as they were considered experts in either providing or directing the provision of services for CYSHCN and families in each county. The results assisted CRS in assessing the State's capacity to provide direct, enabling, population-based, and infrastructure-building services. The responses were stored in an Access database and results were analyzed using both Access and Excel software.

The final CRS Advisory Committee meeting occurred in December 2009, focusing on a presentation of the analyzed data and a discussion of priority needs for CYSHCN. All eight CRS District Supervisors also participated during this final meeting. Attendants were randomly divided into small groups to consider a list of suggested priority needs and were allowed to add or alter it based on their interpretation of the information presented. While in small groups, facilitators led discussions about the information and instructed members to select the top five priority needs for CYSHCN. A second ranking process was then facilitated such that members then ranked those top five priority needs according to their assessment of the feasibility of addressing that need (i.e., how likely it was that the State CSHCN program and the State system of care for CYSHCN could implement activities to address each proposed need). Results were tallied for each group and then presented back to the assembled committee prior to the end of the meeting.

CRS State Office administrative staff, including the State Parent Consultant, and all eight district supervisors (CRS Administrative Team) participated in a follow-up meeting to review the input of the committee and their thoughts on the needs assessment data. The requirements for Block Grant reporting, the six national performance measures for CYSHCN, and information concerning the development of performance measures were also discussed. The group sought to reach consensus on the top priority needs for CYSHCN in the state that CRS has the mission and the capacity to address. Based on the data gathered through the needs assessment process, available resources, input from the advisory group, and content areas of the national performance measures, the group identified three priority needs for further development and planning. Two of these three identified priority needs were re-worded from those presented to the advisory committee to be more inclusive and allow activities that more broadly addressed several separate potential needs, while the third was selected as it was originally written. Three state-negotiated performance measures were drafted, including appropriate measurement strategies. The priority needs and draft measures were then electronically sent back to the CRS Administrative Team for final comment and approval. Annual targets for the upcoming five-year period were set, and annual plan activities were drafted to address the existing national and new state performance measures. The new priority needs, national and state performance measures, and annual plan activities were presented to the State Parent Advisory Committee.

Linkages between Assessment, Capacity, and Priorities

The CRS Needs Assessment Advisory Committee and the CRS Administrative Team were vital links in the assessment process of strengths and needs of CYSHCN and their families as well as in prioritizing needs. The Advisory Committee considered the capacity of the State CSHCN program and the State system of care in general in ranking priority needs. The CRS Administrative Team used this information to narrow down to three priority needs, to develop state performance measures, and to identify activities toward meeting established goals.

SECTION 2 ASSESSMENT OF NEEDS OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Secondary Data

Summary: Socioeconomic differences exist based on geographic regions and Black Belt designation. Children and families living in rural areas and Alabama's Black Belt counties seem to experience greater challenges. These are important considerations for program planning and policy-making.

The following secondary data relating to Alabama CYSHCN were gathered from national, state, and local sources as a part of the needs assessment process:

- In FY 2009, CRS served 12,499 CYSHCN under the age of 21 years. This included 2,472 CSHCN who were new to the program. Of those enrolled in CRS, 3,648 are Supplemental Security Income (SSI) recipients under the age of 16 years (about 37 percent of CRS enrollees who are under 16 years of age).
- In FY 2009, Alabama's Early Intervention System served 6,044 infants and toddlers who had a 25 percent delay in development in at least one domain. This figure represents almost a 40 percent increase over the 4,351 served in FY 2005.
- In Alabama as of December 2008, there were 29,270 children under 18 years of age receiving SSI at any time during the year (about 2.6 percent of the total population under age 18 years). This figure represents a steady increase over the 27,556 recipients in 2005 and the 23,722 recipients in 2000 (about 2.1 percent of the total population in this age range in 2000). The percentage varied across the state from the highest four counties of Perry, Wilcox, Dallas, and Bullock (7.1 percent, 6.5 percent, 5.8 percent, and 5.4 percent respectively) to the lowest two counties of Shelby and St. Clair (1.0 percent and 0.3 percent respectively). All four counties with the highest percentages are rural, southern counties located in the Black Belt region of the state. Both of the two counties with the lowest percentages are in the north-central portion of the state, but one is considered an urban county and the other is considered rural. The above counties differed significantly in certain areas, notably in the percentage of the total child population that is Alabama Medicaid-eligible, the median income, and the percentage of children living in poverty. The rural, southern counties with a higher percentage of SSI recipients under the age of 18 years tended to show higher rates of the described indicators when compared with the north-central counties with the lowest rates. Table 1 below highlights these differences.

city in the county, other cities in the county, and cities that are in more than one county). Figure 2 below displays Alabama’s counties by geographic region.

Figure 2. Alabama’s Geographic Regions by County



In general, the three geographic regions differed significantly in median income, educational attainment, percentage of total child population that is Alabama Medicaid-eligible, percentage of children receiving SSI, and percentage of children living in poverty. The Rural South had a higher percentage of SSI recipients, mean percentage of children under age 18 years living in poverty, and a higher mean percentage of children under age 21 years eligible for Medicaid. Also, they had a lower median income when compared with the Urban and Rural North. Both the Rural North and Rural South were less likely to obtain a high school or higher educational level when compared with persons in the Urban areas. Considering the Black Belt designation, there were also higher levels of poverty, Medicaid eligibility, and SSI, as well as lower levels of educational attainment and median income. Table 2 below highlights these differences.

Table 2. Selected Indicators by County Designation (Geographic Region and Black Belt)

| County Designation | Mean % receiving SSI under age 18 [†] | Mean % under age 18 living in poverty ⁱ | Median income (dollars) ^π | Mean % under age 21 eligible for Medicaid ^β | Mean % over age 25 with HS or greater education ^ο | Mean % over age 25 with BS degree or higher ^Δ |
|-------------------------|--|--|--------------------------------------|--|--|--|
| Urban | 2.5 | 22.1 | 40,830 | 35.8 | 79.0 | 23.2 |
| Rural North | 2.3 | 24.9 | 36,009 | 41.1 | 67.2 | 10.5 |
| Rural South | 3.4 | 32.6 | 32,429 | 49.2 | 68.1 | 12.3 |
| Black Belt [#] | 3.9 | 36.4 | 30,370 | 51.8 | 66.7 | 10.9 |
| Non-Black Belt | 2.3 | 23.9 | 37,504 | 39.9 | 70.8 | 14.5 |
| Statewide | 2.6 | 27.4 | 35,558 | 43.3 | 69.6 | 13.5 |

† Numerator from Social Security Administration, “SSI Recipients by State and County, 2008”; denominator from US. Dept. of Commerce, Bureau of Census, 2000, prepared by Alabama State Data Center at the University of Alabama.
i Percentage of children under age 18 years living below the federal poverty threshold, 2007, Small Area Income and Poverty Estimates, Bureau of Census.
π “County-level Unemployment and Median Household Income for Alabama,” 2008, Bureau of Labor Statistics, Local Area Unemployment Statistics data, Bureau of Census, Small Area Income & Poverty Estimates Program, presented by U.S. Department of Agriculture, Economic Research Service.
β Percentage of total county population under age 21 years eligible for Alabama Medicaid, Alabama Medicaid Agency Statistics, FY 2007.
ο “County-level Education Data for Alabama,” 2000, Bureau of Census, presented by U.S. Department of Agriculture, Economic Research Service.
Δ “County-level Education Data for Alabama,” 2000, Bureau of Census, presented by U.S. Department of Agriculture, Economic Research Service.
The Black Belt encompasses 19 of Alabama’s 67 counties, including Barbour, Bullock, Butler, Choctaw, Clarke, Conecuh, Dallas, Escambia, Greene, Hale, Lowndes, Macon, Marengo, Monroe, Perry, Pickens, Sumter, Washington, and Wilcox. All but three are designated Rural South.

- Alabama-specific data were gathered from two national surveys relevant for CSHCN. The National Survey of Children with Special Health Care Needs is a rich information source for state and national estimates related to critical issues and system development for CSHCN and their families. This includes information related to the six Healthy People 2010 outcomes for this population and the five national performance measures that are based upon them. There have been two iterations of this survey, first in 2001 and next in 2005-2006. The National Survey of Children’s Health provides a comprehensive look at children’s health in general. There have also been two iterations of this survey, 2003 and 2007. Selected information and indicators from both surveys are presented below.

National Survey of Children with Special Health Care Needs (NSCSHCN), 2005-2006

Summary: Overall, CSHCN meet Healthy People 2010 outcomes at similar rates to their national peers. However, there are important subgroup differences – race/ethnicity, age, income, insurance, medical home, and type of need – that require special attention during program planning.

According to the NSCSHCN, 17.1 percent of children ages 0 to 17 years in Alabama are CSHCN, compared with 13.9 percent nationally. This represents a statistically significant difference based on a comparison of the confidence intervals for the two estimates. Based on population estimates for Alabama, this translates to 187,263 CSHCN in the state. This survey allows for analysis by urban/rural profile. Per survey methodology, the geographic categories utilized are based on the Rural Urban Commuting Area (RUCA) rural/urban taxonomy. This is derived from the size and functional relationships of cities and towns as measured by work commuting flows. For more information, go to: <http://depts.washington.edu/uwruca/rural.html>. Although these are more detailed than the county designations utilized for comparisons of secondary data as presented above and also within CRS’s primary data, they do allow for a general comparison with these other data sources.

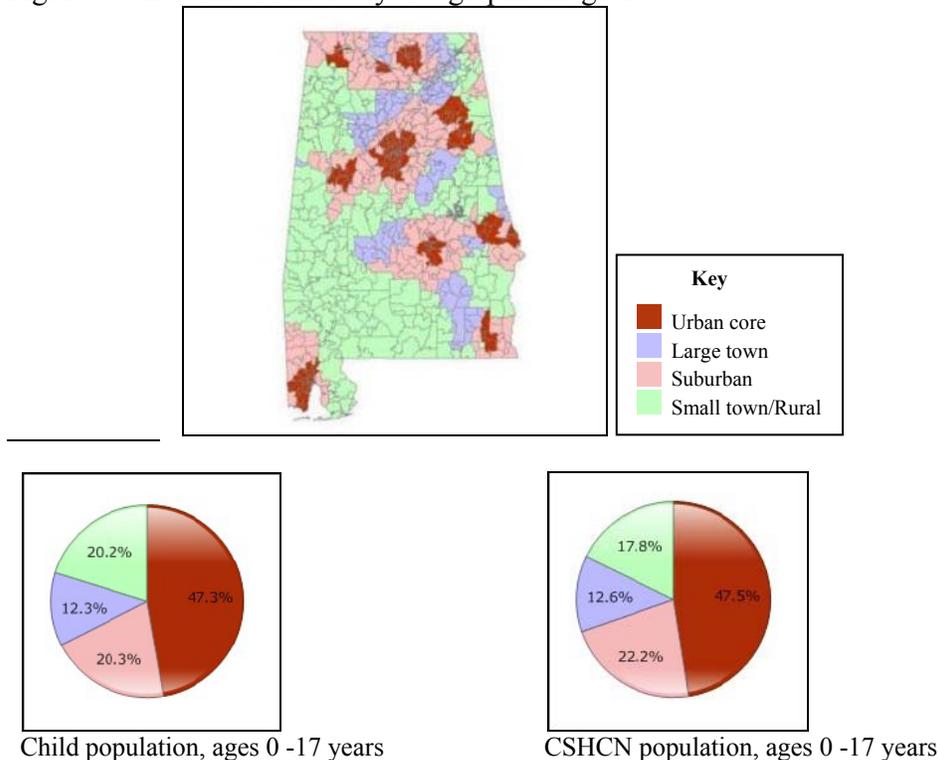
The highest prevalence of CSHCN in Alabama appears to be in suburban areas. Table 3 below illustrates this trend.

Table 3. Prevalence of CSHCN overall and by geographic region

| | Alabama % | Nation % |
|------------------|-----------|----------|
| Overall | 17.1 | 13.9 |
| Urban core | 17.3 | 13.6 |
| Suburban | 18.4 | 14.5 |
| Large town | 17.4 | 15.0 |
| Small town/Rural | 15.1 | 14.0 |

Looking at the Alabama map provided with the survey report, as expected, the urban core areas coincide with the largest cities in the State. These include the Muscle Shoals area, Huntsville, Anniston, Gadsden, Birmingham, Tuscaloosa, Montgomery, Opelika, Dothan, and Mobile. CRS has offices in all of these locations. According to the survey designations, most of the State geographic regions are designated small town/rural. This does coincide with the county designations utilized in analysis of primary data collected for the needs assessment. The population estimates for children ages birth to 17 years and for CSHCN of the same ages is also provided. Almost half of all Alabama children and Alabama CSHCN live in urban core areas. Figure 3 below illustrates these findings.

Figure 3. Alabama CSHCN by Geographic Region



Source: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved [1/13/2010] from www.cshendata.org

Method Note: The geographic categories in this report are based on the Rural Urban Commuting Area (RUCA) rural/urban taxonomy, which is derived from the size and functional relationships of cities and towns as measured by work commuting flows. For more information, go to: <http://depts.washington.edu/uwrUCA/rural.html>

As mentioned above, there are six Healthy People 2010 outcomes for CSHCN and five national performance measures are based upon them. The Healthy People 2010 outcomes cover the broad areas of Family/Professional Partnerships, Medical Home, Adequate Insurance, Early and Continuous Screening, Organized Community-Based Systems, and Transition. There are national performance measures for all but the Early and Continuous Screening outcome. The NSCSHCN provides estimates related to these and allows further stratification of data to allow comparisons across significant sub-populations. Table 4 below provides summary information for success on each outcome measure for the Alabama sample compared with national estimates.

Table 4. Summary of findings by broad area, percent successfully achieved, Alabama and the United States

| Broad Area | Alabama % (CI) | Nation % (CI) |
|-----------------------------------|---------------------------|--------------------------|
| Family/Professional Partnerships | 59.9 (55.7 – 64.1) | 57.4 (56.5 – 58.2) |
| Medical Home | 50.0 (45.6 – 54.4) | 47.1 (46.3 – 48.0) |
| Adequate Insurance | 65.0 (60.8 – 69.1) | 62.0 (61.2 – 62.8) |
| Early and Continuous Screening | 62.3 (58.1 – 66.5) | 63.8 (63.0 – 64.6) |
| Organized Community-Based Systems | 91.7 (89.6 – 93.8) | 89.1 (88.6 – 89.6) |
| Transition | 38.3 (31.7 – 44.9) | 41.2 (39.9 – 42.5) |

Information related to these broad categories is presented below.

- Family/Professional Partnerships

This area is based on Healthy People 2010/MCHB Core Outcome #1: CSHCN whose families are partners in decision-making at all levels and are satisfied with the services they receive. It also relates to National Performance Measure #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision-making at all levels and are satisfied with the services they receive. The data for this indicator come from the NSCSHCN.

In Alabama, about 60 percent of families report success for this measure. The actual estimate, 59.9 percent, is slightly above the national estimate, 57.4 percent, but this is not a significant difference based on a comparison of confidence intervals. These estimates are based on updated data from the 2005-06 iteration of the NSCSHCN. Per survey notes, this outcome can be compared with 2001 results. In the 2005-06 survey versus the 2001 survey, 6.2 percent fewer Alabama families reported success for this measure while numbers for U.S. families were virtually the same.

Comparing across geographic regions, families that live in small town/rural areas tend to report greater success for this measure, though the differences between the regions are not significant when comparing confidence intervals. Table 5 below displays these results.

Table 5. Percent successfully achieved by geographic region, Alabama

| Urban core % (CI) | Suburban % (CI) | Large town % (CI) | Small town/Rural % (CI) |
|--------------------------|------------------------|--------------------------|--------------------------------|
| 58.9 (52.8 – 65.1) | 58.9 (50.2 – 67.6) | 57.0 (45.5 – 68.4) | 65.7 (56.1 – 75.3) |

Looking at success for this measure according to important subgroups reveals several significant differences based on a comparison of confidence intervals. Some additional trends can also be observed; however, they are not significant when comparing confidence intervals. These trends are often mirrored in the national data and result in statistically significant differences by confidence interval. Of note, national confidence intervals are narrower, indicating more precise measurements due to the larger sample size. For several Alabama subgroupings, the confidence intervals are quite large or the sample size is less than 50. This limits the capacity to interpret the data in a reliable manner and may result in the inability to determine whether trends that appear quite different are actually significant. Alabama families are significantly more likely to report success for this measure if they are consistently insured, have a medical home, and have incomes at 400 percent FPL or greater as opposed to 0-199 percent. Also, families of younger CSHCN (0-5 years) are more successful on this measure than are those with older CSHCN (12-17 years) as are those whose child has private insurance only as opposed to those with both private and public coverage. Finally, those families with children who qualified as CSHCN based solely on needing prescription medications were significantly more likely to report success for this measure than were those with CSHCN who qualified because of functional limitations or prescription medication usage and above average service usage together. Table 6 below summarizes these results.

Table 6. Percent successfully achieved by selected indicator, Alabama

| Selected Indicator | Percent Achieved (CI) |
|--|------------------------------|
| Insurance status | |
| Currently insured | 60.3 (56.1 – 64.6) |
| Currently not insured* | 39.2 (13.6 – 64.8) |
| Insurance stability | |
| Insured entire year | 62.3 (58.0 – 66.6) |
| 1 or more periods uninsured, past year | 32.9 (19.5 – 46.2) |
| Insurance type | |
| Private only | 65.6 (60.7 – 70.4) |
| Public only | 57.3 (49.2 – 65.3) |
| Both private and public | 45.3 (30.9 – 59.7) |
| Income level | |
| 0-199% FPL | 53.7 (47.1 – 60.2) |
| 200-299% FPL | 62.3 (52.8 – 71.7) |
| 300-399% FPL | 64.0 (53.9 – 74.2) |
| 400% FPL or greater | 71.8 (65.1 – 78.5) |
| Race/ethnicity | |
| White, non-Hispanic | 63.1 (58.5 – 67.6) |
| Black, non-Hispanic | 54.8 (45.7 – 64.0) |
| Hispanic* | 24.9 (6.7 – 43.2) |
| Multi-racial, non-Hispanic | 54.1 (26.1 – 82.2) |
| Other, non-Hispanic | 78.0 (54.6 – 100) |
| Age | |
| 0-5 years | 70.8 (62.7 – 78.9) |
| 6-11 years | 58.6 (51.8 – 65.4) |
| 12-17 years | 54.6 (47.9 – 61.2) |

| | |
|------------------------------------|--------------------|
| Qualification reason | |
| Functional limitations | 48.5 (39.4 – 57.6) |
| Managed by Rx meds | 69.8 (64.4 – 75.3) |
| Above routine need/use of services | 60.6 (46.5 – 74.6) |
| Rx meds and service use | 49.8 (40.2 – 59.4) |
| Medical home | |
| Yes | 81.5 (76.9 – 86.1) |
| No | 38.8 (32.6 – 45.0) |

*Estimates based on sample sizes too small to meet standards for reliability or precision

■ Shaded areas indicate significant differences exist within the subgroup based on comparison of confidence intervals

■ Medical Home

This area is based on Healthy People 2010/MCHB Core Outcome # 2: CSHCN receive coordinated, ongoing, comprehensive care within a medical home. It also relates to National Performance Measure #3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. The data for this indicator come from the NSCSHCN.

In Alabama, 50 percent of families report success for this measure. This is slightly above the national estimate, 47.1 percent, but this is not a significant difference based on a comparison of confidence intervals. These estimates are based on updated data from the 2005-06 iteration of the NSCSHCN. Per survey notes, this outcome cannot be compared to 2001 results due to changes in methodology. Most families did report having a source for sick care other than an emergency room (93.6 percent). CSHCN with medical homes were statistically significantly less likely to have unmet health service or equipment needs than were those without medical homes. Of those with medical homes, 94.4 percent had no unmet needs compared with 80.8 percent of those without medical homes.

Comparing across geographic regions, families that live in suburban areas tend to report greater success for this measure, though the differences between the regions are not significant when comparing confidence intervals. Table 7 below displays these results.

Table 7. Percent successfully achieved by geographic region, Alabama

| Urban core % (CI) | Suburban % (CI) | Large town % (CI) | Small town/Rural % (CI) |
|--------------------|--------------------|--------------------|-------------------------|
| 49.3 (42.9 – 55.8) | 53.1 (44.2 – 62.1) | 46.6 (34.4 – 58.9) | 50.2 (39.5 – 60.9) |

Looking at success for this measure according to important subgroups reveals several significant differences based on a comparison of confidence intervals. Some additional trends can also be observed; however, they are not significant when comparing confidence intervals. These trends are often mirrored in the national data and result in statistically significant differences by confidence interval. There are similar limitations based on confidence interval range and sample size. Alabama families are significantly more likely to report success for this measure if they are consistently insured and if they have incomes at 300-399 percent FPL or 400 percent FPL or greater as opposed to 0-199 percent. Also, families of CSHCN with private insurance only are more likely to have a medical home as opposed to those with both private and public coverage. Finally, those families with children who qualified as CSHCN based solely on needing prescription medications were

significantly more likely to report success for this measure than were those with CSHCN who qualified for other reasons. Table 8 below summarizes these results.

Table 8. Percent successfully achieved by selected indicator, Alabama

| Selected Indicator | Percent Achieved (CI) |
|--|------------------------------|
| Insurance status | |
| Currently insured | 50.2 (45.8 – 54.7) |
| Currently not insured* | 31.4 (6.3 – 56.5) |
| Insurance stability | |
| Insured entire year | 51.8 (47.2 – 56.3) |
| 1 or more periods uninsured, past year | 29.4 (15.4 – 43.4) |
| Insurance type | |
| Private only | 59.6 (54.4 – 64.8) |
| Public only | 42.4 (33.9 – 50.8) |
| Both private and public | 31.9 (17.7 – 46.0) |
| Income level | |
| 0-199% FPL | 40.5 (33.8 – 47.3) |
| 200-299% FPL | 52.0 (42.1 – 61.9) |
| 300-399% FPL | 64.6 (54.3 – 74.9) |
| 400% FPL or greater | 64.7 (57.1 – 72.3) |
| Race/ethnicity | |
| White, non-Hispanic | 54.5 (49.7 – 59.4) |
| Black, non-Hispanic | 40.5 (31.2 – 49.9) |
| Hispanic* | 39.9 (16.4 – 63.4) |
| Multi-racial, non-Hispanic | 53.7 (26.7 – 80.8) |
| Other, non-Hispanic* | 48.5 (17.8 – 79.1) |
| Age | |
| 0-5 years | 51.3 (41.7 – 60.9) |
| 6-11 years | 49.9 (42.7 – 57.0) |
| 12-17 years | 49.3 (42.5 – 56.1) |
| Qualification reason | |
| Functional limitations | 34.4 (25.5 – 43.3) |
| Managed by Rx meds | 62.5 (56.6 – 68.4) |
| Above routine need/use of services | 38.6 (23.8 – 53.4) |
| Rx meds and service use | 42.8 (33.0 – 52.5) |

*Estimates based on sample sizes too small to meet standards for reliability or precision

☐ Shaded areas indicate significant differences exist within the subgroup based on comparison of confidence intervals

■ Adequate Insurance

This area is based on Healthy People 2010/MCHB Core Outcome #3: CSHCN have adequate public and/or private insurance to pay for the services they need. It also relates to National Performance Measure #4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. The data for this indicator come from the NSCSHCN.

In Alabama, 65 percent of families report success for this measure. This is slightly above the national estimate, 62 percent, but this is not a significant difference based on a comparison of

confidence intervals. These estimates are based on updated data from the 2005-06 iteration of the NSCSHCN. Per survey notes, this outcome can be compared to 2001 results. Per the 2005-06 survey versus the 2001 survey, 5.4 percent more Alabama families and 2.4 percent more U.S. families reported adequate insurance.

Comparing across geographic regions, families that live in large towns tend to report greater success for this measure, though the differences between the regions are not significant when comparing confidence intervals. Table 9 below displays these results.

Table 9. Percent successfully achieved by geographic region, Alabama

| Urban core % (CI) | Suburban % (CI) | Large town % (CI) | Small town/Rural % (CI) |
|--------------------------|------------------------|--------------------------|--------------------------------|
| 68.4 (62.4 – 74.4) | 64.1 (55.4 – 72.8) | 69.1 (58.4 – 79.7) | 54.0 (43.6 – 64.4) |

Looking at success for this measure according to important subgroups reveals several significant differences based on a comparison of confidence intervals. Some additional trends can also be observed; however, they are not significant when comparing confidence intervals. These trends are often mirrored in the national data and result in statistically significant differences by confidence interval. There are similar limitations based on confidence interval range and sample size. Alabama families are significantly more likely to report success for this measure if they are consistently insured, have a medical home, and have incomes at 400 percent FPL or greater as opposed to 0-199 percent FPL. Also, families of CSHCN with private insurance only are more likely to have adequate insurance as opposed to those with both private and public coverage. Finally, those families with children who qualified as CSHCN based solely on needing prescription medications were significantly more likely to report success for this measure than were those with CSHCN who qualified based on functional limitations. Table 10 below summarizes these results.

Table 10. Percent successfully achieved by selected indicator, Alabama

| Selected Indicator | Percent Achieved (CI) |
|----------------------------|------------------------------|
| Insurance type | |
| Private only | 69.5 (64.6 – 74.4) |
| Public only | 67.6 (59.8 – 75.5) |
| Both private and public | 46.1 (32.0 – 60.3) |
| Income level | |
| 0-199% FPL | 59.5 (53.0 – 66.0) |
| 200-299% FPL | 64.7 (55.5 – 73.9) |
| 300-399% FPL | 70.1 (59.9 – 80.3) |
| 400% FPL or greater | 76.3 (69.7 – 82.9) |
| Race/ethnicity | |
| White, non-Hispanic | 66.4 (61.7 – 71.0) |
| Black, non-Hispanic | 63.2 (54.2 – 72.1) |
| Hispanic | 44.5 (20.6 – 68.4) |
| Multi-racial, non-Hispanic | 62.3 (37.0 – 87.5) |
| Other, non-Hispanic | 61.1 (30.7 – 91.6) |
| Age | |
| 0-5 years | 67.0 (58.3 – 75.8) |
| 6-11 years | 63.9 (57.1 – 70.8) |
| 12-17 years | 64.8 (58.3 – 71.3) |

| | |
|------------------------------------|--------------------|
| Qualification reason | |
| Functional limitations | 54.2 (45.1 – 63.3) |
| Managed by Rx meds | 71.2 (65.6 – 76.9) |
| Above routine need/use of services | 63.0 (47.4 – 78.5) |
| Rx meds and service use | 63.3 (53.9 – 72.7) |
| Medical home | |
| Yes | 76.4 (70.9 – 81.9) |
| No | 53.9 (47.6 – 60.1) |

■ Shaded areas indicate significant differences exist within the subgroup based on comparison of confidence intervals

- Early and Continuous Screening

This area is based on Healthy People 2010/MCHB Core Outcome #4: CSHCN who are screened early and continuously for special health care needs. There is no corresponding national performance measure. The 2005-06 National Survey of CSHCN included baseline results for early and continuous screening for special health care needs. Overall, 62.3 percent of Alabama families with CSHCN reported success for this measure versus 63.8 percent of U.S. families, though this is not a significant difference based on a comparison of confidence intervals.

Comparing across geographic regions, families that live in urban core and suburban areas tend to report greater success for this measure. Based on a comparison of confidence intervals, the differences are significant when compared with the experience of CSHCN living in small town/rural areas. Table 11 below displays these results.

Table 11. Percent successfully achieved by geographic region, Alabama

| Urban core % (CI) | Suburban % (CI) | Large town % (CI) | Small town/Rural % (CI) |
|--------------------|--------------------|----------------------|-------------------------|
| 68.5 (62.6 – 74.3) | 69.3 (60.7 – 77.9) | 50.4 (38.7 – 62.1 0) | 45.5 (35.3 – 55.7) |

Looking at success for this measure according to important subgroups reveals several significant differences based on a comparison of confidence intervals. Some additional trends can also be observed; however, they are not significant when comparing confidence intervals. These trends are often mirrored in the national data and result in statistically significant differences by confidence interval. As described earlier, Alabama data have limitations based on confidence interval range and sample size. Alabama families are significantly more likely to report success for this measure if they are consistently insured, have private insurance only as opposed to public only, and have incomes at 300-399 percent FPL or 400 percent FPL or greater as opposed to 0-199 percent FPL. Table 12 below summarizes these results.

Table 12. Percent successfully achieved by selected indicator, Alabama

| Selected Indicator | Percent Achieved (CI) |
|--|-----------------------|
| Insurance status | |
| Currently insured | 62.6 (58.3 – 66.9) |
| Currently not insured | 49.1 (22.4 – 75.7) |
| Insurance stability | |
| Insured entire year | 63.3 (58.9 – 67.7) |
| 1 or more periods uninsured, past year | 50.8 (36.1 – 65.4) |

| | |
|------------------------------------|--------------------|
| Insurance type | |
| Private only | 70.8 (66.1 – 75.4) |
| Public only | 53.5 (45.3 – 61.8) |
| Both private and public | 54.5 (40.1 – 68.9) |
| Income level | |
| 0-199% FPL | 55.6 (49.0 – 62.2) |
| 200-299% FPL | 67.5 (58.5 – 76.5) |
| 300-399% FPL | 73.4 (64.4 – 82.4) |
| 400% FPL or greater | 69.7 (62.6 – 76.8) |
| Race/ethnicity | |
| White, non-Hispanic | 65.8 (61.3 – 70.3) |
| Black, non-Hispanic | 54.9 (45.6 – 64.2) |
| Hispanic | 59.6 (34.3 – 84.8) |
| Multi-racial, non-Hispanic | 57.0 (30.5 – 83.4) |
| Other, non-Hispanic | 83.0 (59.7 – 100) |
| Age | |
| 0-5 years | 54.9 (45.6 – 64.3) |
| 6-11 years | 68.1 (61.5 – 74.6) |
| 12-17 years | 60.6 (53.9 – 67.3) |
| Qualification reason | |
| Functional limitations | 63.2 (54.4 – 71.9) |
| Managed by Rx meds | 62.0 (56.0 – 67.9) |
| Above routine need/use of services | 61.4 (46.2 – 76.6) |
| Rx meds and service use | 62.5 (52.7 – 72.2) |
| Medical home | |
| Yes | 65.3 (59.2 – 71.4) |
| No | 58.8 (52.6 – 65.0) |

■ Shaded areas indicate significant differences exist within the subgroup based on comparison of confidence intervals

■ Organized Community-Based Systems

This area is based on Healthy People 2010/MCHB Core Outcome #5: CSHCN whose community-based service systems are organized for ease of use. It also relates to National Performance Measure #5: The percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. The data for this indicator come from the NSCSHCN.

In Alabama, 91.7 percent of Alabama families with CSHCN reported success for this measure, versus 89.1 percent of U.S. families, but this is not a significant difference based on a comparison of confidence intervals. These estimates are based on updated data from the 2005-06 iteration of the NSCSHCN. Per survey notes, this outcome cannot be compared to 2001 results due to changes in methodology.

Comparing across geographic regions, there is little variation, though families that live in large towns tend to report slightly less success for this measure. The differences between the regions are not significant when comparing confidence intervals. Table 13 below displays these results.

Table 13. Percent successfully achieved by geographic region, Alabama

| Urban core % (CI) | Suburban % (CI) | Large town % (CI) | Small town/Rural % (CI) |
|--------------------|--------------------|--------------------|-------------------------|
| 92.5 (89.3 – 95.6) | 92.0 (87.8 – 96.1) | 85.7 (78.5 – 93.0) | 93.5 (89.0 – 98.0) |

Looking at success for this measure according to important subgroups reveals several significant differences based on a comparison of confidence intervals. Some additional trends can also be observed; however, they are not significant when comparing confidence intervals. These trends are often mirrored in the national data and result in statistically significant differences by confidence interval. There are similar limitations based on confidence interval range and sample size. Alabama families are significantly more likely to report success for this measure if they have a medical home and if their children qualified as CSHCN based solely on needing prescription medications as opposed to functional limitations or prescription medications and service use together. Also, those classified as other, non-Hispanic appeared to report greater success for this measure, though the sample size was very small and there is no reported range for the confidence interval. Table 14 below summarizes these results.

Table 14. Percent successfully achieved by selected indicator, Alabama

| Selected Indicator | Percent Achieved (CI) |
|--|-----------------------|
| Insurance status | |
| Currently insured | 91.9 (89.7 – 94.0) |
| Currently not insured | 82.3 (62.9 – 100) |
| Insurance stability | |
| Insured entire year | 92.5 (90.3 – 94.6) |
| 1 or more periods uninsured, past year | 82.5 (72.2 – 92.9) |
| Insurance type | |
| Private only | 93.5 (91.1 – 96.0) |
| Public only | 90.7 (86.7 – 94.8) |
| Both private and public | 87.2 (78.6 – 95.7) |
| Income level | |
| 0-199% FPL | 90.5 (87.2 – 93.8) |
| 200-299% FPL | 89.0 (82.4 – 95.6) |
| 300-399% FPL | 91.9 (87.0 – 96.7) |
| 400% FPL or greater | 96.3 (93.7 – 99.0) |
| Race/ethnicity | |
| White, non-Hispanic | 91.5 (88.9 – 94.0) |
| Black, non-Hispanic | 92.6 (88.4 – 96.8) |
| Hispanic | 80.2 (61.2 – 99.1) |
| Multi-racial, non-Hispanic | 85.4 (70.3 – 100) |
| Other, non-Hispanic | 100 (100 – 100) |
| Age | |
| 0-5 years | 92.6 (88.3 – 96.8) |
| 6-11 years | 91.7 (88.2 – 95.1) |
| 12-17 years | 91.2 (87.7 – 94.7) |
| Qualification reason | |
| Functional limitations | 80.7 (74.3 – 87.1) |
| Managed by Rx meds | 97.9 (96.1 – 99.7) |
| Above routine need/use of services | 92.7 (86.5 – 98.9) |
| Rx meds and service use | 89.3 (83.9 – 94.6) |

| | |
|---------------------|--------------------|
| Medical home | |
| Yes | 97.7 (96.1 – 99.2) |
| No | 85.6 (81.6 – 89.7) |

■ Shaded areas indicate significant differences exist within the subgroup based on comparison of confidence intervals

- Transition

This area is based on Healthy People 2010/MCHB Core Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adulthood (health care, work, and independence). It also relates to National Performance Measure #6: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. The data for this indicator come from the NSCSHCN. In Alabama, 38.3 percent of Alabama families with CSHCN reported success for this measure versus 41.2 percent of U.S. families, but this is not a significant difference based on a comparison of confidence intervals. These estimates are based on updated data from the 2005-06 iteration of the NSCSHCN. Previous Alabama estimates for this measure were not reliable and, per survey notes, this outcome cannot be compared to 2001 results due to changes in methodology.

Comparing across geographic regions, families that live in suburban areas tend to report greater success for this measure, though the differences between the regions are not significant when comparing confidence intervals and the estimate for those in large towns did not meet reliability and precision standards. Table 15 below displays these results.

Table 15. Percent successfully achieved by geographic region, Alabama

| Urban core % (CI) | Suburban % (CI) | Large town % (CI) | Small town/Rural % (CI) |
|--------------------|--------------------|--------------------|-------------------------|
| 36.2 (27.2 – 45.2) | 49.2 (35.1 – 63.3) | 26.5* (7.1 – 45.9) | 37.7 (20.8 – 54.6) |

*Estimates based on sample sizes too small to meet standards for reliability or precision

In many cases, when attempting to look at the Alabama data related to success for this measure by subgroups, the sample sizes were too small to meet reliability and precision standards. When those were met, often the confidence interval ranges were quite large, so even trends that are significant in the national data could not be supported. There are two significant differences based on a comparison of confidence intervals. Alabama families are significantly more likely to report success for this measure if they have a medical home and if they have incomes at 400 percent FPL or greater as opposed to 0-199 percent. Table 16 below summarizes these results.

Table 16. Percent successfully achieved by selected indicator, Alabama

| Selected Indicator | Percent Achieved (CI) |
|---|-----------------------|
| Insurance status | |
| Currently insured | 39.1 (32.4 – 45.8) |
| Currently not insured | 0 |
| Insurance stability | |
| Insured entire year | 42.1 (35.0 – 49.2) |
| 1 or more periods uninsured, past year* | 9.5 (0 – 20.4) |

| | |
|------------------------------------|--------------------|
| Insurance type | |
| Private only | 52.2 (44.3 – 60.2) |
| Public only | 20.0 (8.6 – 31.4) |
| Both private and public* | 27.5 (5.2 – 49.9) |
| Income level | |
| 0-199% FPL | 23.1 (13.7 – 32.4) |
| 200-299% FPL | 48.0 (32.8 – 63.2) |
| 300-399% FPL | 49.5 (30.6 – 68.4) |
| 400% FPL or greater | 60.0 (48.8 – 71.2) |
| Race/ethnicity | |
| White, non-Hispanic | 44.2 (36.7 – 51.6) |
| Black, non-Hispanic | 26.7 (13.3 – 40.2) |
| Hispanic* | 40.8 (7.8 – 73.9) |
| Multi-racial, non-Hispanic* | 19.5 (0 – 55.2) |
| Other, non-Hispanic* | 34.2 (0 – 85.9) |
| Qualification reason | |
| Functional limitations | 29.9 (16.3 – 43.6) |
| Managed by Rx meds | 45.0 (35.5 – 54.4) |
| Above routine need/use of services | 46.3 (22.5 – 70.1) |
| Rx meds and service use | 31.2 (18.1 – 44.2) |
| Medical home | |
| Yes | 56.9 (47.2 – 66.6) |
| No | 22.5 (14.8 – 30.1) |

*Estimates based on sample sizes too small to meet standards for reliability or precision

■ Shaded areas indicate significant differences exist within the subgroup based on comparison of confidence intervals

■ Care Coordination

Although there is no Healthy People 2010 outcome or National Performance Measure associated with care coordination, this is a service that is critical for CYSHCN and their families so that they may best benefit from the services they need and receive. It is also a key service provided by CRS. The NSCSHCN provides information on this area of interest via a derived indicator. In Alabama, 62.2 percent of CSHCN who needed care coordination received all the needed components of the service. This was slightly above the estimate for the nation, 59.2 percent, but the difference was not significant based upon a comparison of confidence intervals. Taken in reverse, this means that almost 40 percent of Alabama CSHCN did not receive one or more elements of care coordination.

National Survey of Children’s Health, 2007

The National Survey of Children’s Health (NSCH) offers a wide range of information, but only selected indicators were analyzed, chosen because they add to the findings gathered from NSCSHCN and act as an adjunct to the primary data collected by CRS. The selected indicators are related to family supports, neighborhood, and CSHCN involvement in community and school activities.

Based on a comparison of confidence intervals, parents of Alabama CSHCN are more likely to experience child care issues and job-related changes due to child care issues than are Alabama parents of non-CHSCN. This trend is also seen nationally. The Alabama data are not significantly

different from the national estimates. Alabama non-CSHCN are more likely to live in supportive neighborhoods than are their national peers; however, there are no differences seen for CSHCN. Supportive neighborhoods are defined based on questions related to neighbors helping each other and watching out for each others’ children. Alabama CSHCN and Alabama non-CSHCN are more likely than their national peers to live in neighborhoods with no amenities (parks, recreation centers, sidewalks, or libraries). No specific CSHCN differences are noted. Nationally, non-CSHCN are more likely to participate in sports teams/lessons, clubs, or organizations outside of schools than are their CSHCN peers. Although this trend is observed in the Alabama data, it is not significant by confidence interval. Table 17 below summarizes these results.

Table 17. Selected indicators, CSHCN vs. non-CSHCN, Alabama vs. U.S.

| Indicator | Alabama % (CI) | | Nation % (CI) | |
|---|---------------------|---------------------|---------------------|---------------------|
| | CSHCN | Non-CSHCN | CSHCN | Non-CSHCN |
| Parents had problems with child care or job-related changes due to child care reasons | 52.4 (33.9-70.9) | 30.1 (23.8-36.3) | 37.1 (33.1-41.0) | 29.8 (28.4-31.3) |
| Children living in supportive neighborhoods | 78.5 (71.3-85.7) | 87.6 (84.9-90.2) | 80.4 (78.9-81.9) | 83.9 (83.2-84.6) |
| Children living in neighborhoods with no amenities | 15.2 (9.4-21.0) | 11.1 (8.7-13.5) | 4.7 (4.0-5.3) | 4.6 (4.2-4.9) |
| Children usually/always feel safe at school | 85.5 (79.3-91.8) | 86.2 (82.4-90.0) | 88.8 (87.5-90.1) | 89.8 (89.0-90.6) |
| Children participate in one or more organized activities outside school | 77.4 (69.8-84.9) | 79.7 (75.6-83.9) | 77.2 (75.4-79.0) | 81.7 (80.7-82.7) |

Primary Data

Primary data were collected from families, youth, and providers to more adequately assess the current status of Alabama’s CYSHCN. Findings from three main methodologies – focus groups, surveys, and key informant interviews – are described next.

County-Level Provider Surveys

Summary: Differences exist for barriers and service availability by geographic region and Black Belt designation. Overall, community-based services tend to be more difficult to obtain than health services. Respite, summer/after-school care, and transportation tend to be the most difficult services to obtain statewide.

CRS staff facilitated the completion of surveys on a county-by-county basis, utilizing various methods to obtain input from providers and agencies serving CYSHCN in the county. There were 501 total respondents counted across all counties, with a wide range of community providers and partners represented. Given the increased number of participants and multi-agency involvement, the data are considered to be a valid representation of actual barriers and conditions at the county level.

As in previous years, data were analyzed not only in aggregate, but also according to geographic categories and Black Belt designation. Statewide data from the FY 2009-10 MCH needs assessment were compared with that gathered during the 1994, 1999, and 2004 needs assessments whenever possible. Some differences in analyzed responses were noted by geographic region.

Barriers

A list was provided of 14 potential barriers to receiving services that might be experienced by CYSHCN and their families. Respondents were to answer “yes” or “no” to indicate whether that particular item posed a barrier to CYSHCN and their families receiving needed services. Respondents were then asked to assign a rank for the importance level of that barrier as either “high,” “medium,” or “low.” The ratings basically asked the respondents to consider how much of a problem the identified barrier was for CYSHCN and their families. Only those barriers actually identified as present in the county were ranked. A numeric value was assigned to these designations to assist with ranking. Responses were tabulated to obtain the number of counties that indicated the item was a barrier as well as the total priority score from the rankings. First, barriers were ranked in order of the number of counties that indicated the item as a barrier. Ties were then broken based on the priority ranking score. In the event of a tie for both scores, the barriers were presented in the order in which they appeared in the survey. Barriers were ranked statewide and by geographic region and Black Belt designation.

Statewide Barriers

Of the top five barriers for the 2009 needs assessment cycle, three were also in the top five in 2004 and all five were in the top five in 1999. “Transportation” continues to be the number one barrier identified by providers, and this follows a trend that has been observed since 1994. “Families unsure how to use the system” has been the number two or three barrier since 1999. “Lack of child care” continues to be in the top five, as has also been the case since 1994. “Lack of information on resources and health needs” and “insurance does not adequately cover needed health and related services” have both moved in to the top five from number 8 and number 11, respectively, in 2004. “Providers not available” was the number four barrier in 2004, but has dropped to number 10 for 2009. Another significant change is seen for “costs of services are too high.” This barrier was ranked as number six by providers in 2004, but has dropped to number 12 in 2009. Other barriers were ranked at similar levels to previous needs assessment years. Table 18 below summarizes these results.

Table 18. Barriers to receiving services for CYSHCN and families, statewide, by needs assessment cycle

| 2009 (in rank order) | 2004 rank | 1999 rank | 1994 rank |
|--|----------------------|----------------------|----------------------|
| 1. Transportation | 1 | 1 | 1 |
| 2. Families unsure how to use the system | 3 | 2 | 7 |
| 3. Lack of child care | 5 | 5 | 4 |
| 4. Lack of information on resources and health needs | 8 | 5 | 10 |
| 5. Insurance does not adequately cover needed health and related services | 11 | 5 | 6 |
| 6. Lack of health insurance | 7 | 3 | 10 |
| 7. Inadequate transition | 9 | n/a | n/a |
| 8. Cultural/language barriers | 10 | 7 | 14 |
| 9. Lack of facilities with convenient locations | 12 | 8 | 9 |
| 10. Providers not available | 4 | 4 | 5 |
| 11. Lack of facilities with convenient hours | 13 | 9 | 13 |
| 12. Costs of services are too high | 6 | 6 | 2 |
| 13. Other | 15 | 11 | 8 |
| 14. State policy or administrative barriers | 14 | 10 | 11 |

Source: County provider survey, 2009

Barriers According to Geographic Area

Responses were stratified according to geographic region and data were compared to statewide findings as well as between groups. Statewide, and for the Rural North and Rural South geographic regions, “transportation” was ranked as the number one barrier to care for CYSHCN. In 2004, this barrier was also ranked as the number one barrier for the Urban region; however, for this needs assessment cycle, it has dropped to number three in that area. In addition to “transportation,” the only other barrier that appeared in the top five list across all three geographic regions was “families unsure how to use the system.” Differences were noted geographically in further rankings. For example, “lack of child care” was mentioned in the top five list for Rural North or Rural South, but not for Urban areas. The barrier “insurance does not adequately cover needed health and related services” illustrates another example of this geographic variation. This barrier is ranked as one of the top five barriers for the Urban regions, but not for the Rural North and Rural South regions. Table 19 below summarizes the results across all 3 geographic regions.

Table 19. Top five barriers to obtaining services for CYSHCN and families, by geographic region, 2009

| Rank | Rural North | Rural South | Urban |
|------|--|--|--|
| 1 | Transportation | Transportation | Families unsure how to use the system |
| 2 | Families unsure how to use the system | Inadequate transition | Cultural/language barriers |
| 3 | Lack of child care | Families unsure how to use the system | Transportation |
| 4 | Lack of information on resources and health needs | Lack of facilities with convenient hours | Insurance does not adequately cover needed health and related services |
| 5 | Lack of health insurance <i>and</i> Lack of facilities with convenient locations | Lack of child care | Other |

Source: County provider survey

Barriers According to Black Belt Designation

Responses were also stratified according to Black Belt designation and data were compared between groups. “Transportation” was the number one barrier for both groups. “Families unsure how to use the system” was in the top five list for both groups. Specifically for the Black Belt region, “lack of information on resources and health needs” and “providers not available” were top five barriers. Given the known lack of resources in the area, this is not surprising. Perhaps “inadequate transition” being listed also is partially explained by the lack of resources in the area. In the non-Black Belt region, consistency and adequacy of health insurance were top five issues, as were “cultural/language barriers.” Table 20 below summarizes the results between the two groups.

Table 20. Top five barriers to obtaining services for CYSHCN and families, by Black Belt, 2009

| Rank | Black Belt | Non-Black Belt |
|------|---|--|
| 1 | Transportation | Transportation |
| 2 | Inadequate transition | Families unsure how to use the system |
| 3 | Lack of information on resources and health needs | Insurance does not adequately cover needed health and related services |
| 4 | Families unsure how to use the system <i>and</i> Lack of child care | Cultural/language barriers |
| 5 | Providers not available | Lack of health insurance |

Source: County provider survey

Services

The county-level survey tool included questions related to the availability of 23 specific services that may be utilized by CYSHCN and their families. These services were divided into health services and community-based services. Respondents were first asked to consider whether these services were available within the county. If a service was not available within the county, the respondents were then asked to consider whether it was available in an adjoining or neighboring county. Comparisons

could then be made statewide, by geographic region, and by Black Belt designation. Service availability questions were included in the 1999 and 2004 needs assessment cycles, but results are not truly comparable. Previously, the focus was on availability of services in the county. The leadership team for the 2009 needs assessment felt that service availability should not focus simply on the county, but the surrounding area given that certain services would not be expected within each county. For purposes of categorization, difficulty in obtaining services or less than optimal service availability was considered if a service was not available (within county or in adjoining county) in at least 90 percent of counties. Table 21 below displays statewide availability of services either within counties or in neighboring counties. Most services are available either within the county or in a neighboring county. Three community-based services – respite, summer/after school care, and transportation – were available (in county or in adjoining county) in less than 90 percent of counties.

Table 21. Statewide service availability, 2009

| Service | Statewide (n=67) | |
|---------------------------------|---|-----|
| | Available within county or adjoining county | % |
| Health Services | | |
| Primary Care | 67 | 100 |
| Specialty Care | 65 | 97 |
| Emergency Care | 66 | 99 |
| MH/Behavioral | 65 | 97 |
| Dev Screening | 66 | 99 |
| Dental | 66 | 99 |
| PT | 67 | 100 |
| OT | 64 | 96 |
| SLP | 66 | 97 |
| Nutrition | 67 | 100 |
| Vision | 66 | 99 |
| Hearing | 63 | 94 |
| Equipment/Braces | 61 | 91 |
| Community-based Services | | |
| Care Coordination | 66 | 99 |
| Daycare | 64 | 96 |
| EI | 67 | 100 |
| Education | 67 | 100 |
| Family Support | 63 | 94 |
| Transition | 63 | 94 |
| Recreation | 63 | 94 |
| Respite | 57 | 85 |
| Summer/After-School Care | 58 | 87 |
| Transportation | 58 | 87 |

Source: County-level Provider Survey

Shaded services available in less than 90% of counties

Comparing service availability across geographic areas and Black Belt designation revealed differences. Rural North counties had similar availability to the statewide numbers, with only respite, summer/after-school care, and transportation available in less than 90 percent of counties. Urban counties showed less than 90 percent service availability for only respite and summer/after-school care. Rural South counties had considerably more services that were not available in at least 90 percent of the counties. In addition to respite, summer/after-school care, and transportation, other services included hearing, equipment/braces, family support, transition, and recreation. All three

geographic areas had community-based services that were not available either within the county or in an adjoining county for less than 90 percent of the counties. However, Rural South counties not only had more community-based services that were less available, but also were the only counties to report health service availability difficulties as well. Findings for counties within the Black Belt designation were the same as those for the Rural South. Tables 22 and 23 below display services that were difficult to obtain by geographic region and Black Belt designation.

Table 22. Service availability at less than 90 percent by county designation (within county or in adjoining county), 2009

| Service | Rural North (n=29) | | Rural South (n=26) | | Urban (n=12) | |
|---------------------------------|--------------------|----|--------------------|----|--------------|-----|
| | Total | % | Total | % | Total | % |
| Health Services | | | | | | |
| Hearing | 28 | 97 | 23 | 88 | 12 | 100 |
| Equipment/Braces | 27 | 93 | 22 | 85 | 12 | 100 |
| Community-based Services | | | | | | |
| Family Support | 28 | 97 | 23 | 88 | 12 | 100 |
| Transition | 28 | 97 | 23 | 88 | 12 | 100 |
| Recreation | 28 | 97 | 23 | 88 | 12 | 100 |
| Respite | 25 | 86 | 22 | 85 | 10 | 83 |
| Summer/After-School Care | 25 | 86 | 23 | 88 | 10 | 83 |
| Transportation | 25 | 86 | 22 | 85 | 11 | 92 |

Source: County-level Provider Survey Shaded areas are service availabilities at less than 90%

Table 23. Service availability at less than 90 percent by Black Belt designation (within county or in adjoining county), 2009

| Service | Non-Black Belt (n=48) | | Black Belt (n=19) | |
|---------------------------------|-----------------------|----|-------------------|----|
| | Total | % | Total | % |
| Health Services | | | | |
| Hearing | 47 | 98 | 16 | 84 |
| Equipment/Braces | 46 | 96 | 15 | 79 |
| Community-based Services | | | | |
| Family Support | 47 | 98 | 16 | 84 |
| Transition | 47 | 98 | 16 | 84 |
| Recreation | 47 | 98 | 16 | 84 |
| Respite | 42 | 88 | 15 | 79 |
| Summer/After-School Care | 42 | 88 | 16 | 84 |
| Transportation | 41 | 85 | 17 | 89 |

Source: County-level Provider Survey

Key Informant Interviews

Summary: Although most services are available either within counties or in adjoining counties statewide, a significant number of services (especially community-based services) are considered “harder than you would expect” for CYSHCN and families to obtain. Regional and Black Belt designation differences exist. Identified greatest needs tended to be health service needs, except for the Urban counties. Alabama’s overall system of care for CYSHCN and families is rated “average.”

After the county-level provider survey data were analyzed, the smaller CRS needs assessment team determined that clarification was needed relative to service availability in the State. Specifically, the team felt that not enough was known about experiences with service availability at the county level in terms of burden or difficulty in obtaining services. The county-level provider surveys gave an idea of the availability of services (either within the county or in a neighboring county), but did not provide an idea of what that really meant to people living in communities. For example, a service could indeed be available in a county, but could still be a burden to obtain based on a variety of issues (waiting lists, number of providers, expertise, travel, etc.). Also, a service with availability in a neighboring county might be relatively easy or significantly difficult to obtain depending upon geographic location. To that end, the team decided to conduct key informant interviews with a goal of clarifying what had been learned from providers and filling in gaps related to difficulty/burden. CRS District Supervisors and Office Coordinators were selected as key informants as they are seen as having expert knowledge in advocating for and providing services to CYSHCN and their families (either directly or through administration/oversight) at the community level. All 14 interviews were conducted by the CRS Needs Assessment Coordinator. A three-question tool was developed in collaboration with UAB School of Public Health. The interview included assessments of the level of burden or difficulty faced by families living in the county in obtaining health and community-based services, the effectiveness of the overall system of care for CYSHCN and families in the county, and the three greatest service needs in the county.

Level of Difficulty

The same list of 23 health and community-based services that was presented in the county-level provider survey and family survey (see next section) was presented to key informants. Respondents were asked to assess the level of difficulty or burden faced by families in the county in obtaining the selected services. They were instructed to consider how hard it was for families to get the services, regardless of where they get them (within county, in neighboring county, further away). This assessment was based on a 1 – 3 Likert scale for “harder than you would expect,” “about what you would expect,” and “easier than you would expect.” Statewide, no services averaged “easier than you would expect.” A slight majority of health services averaged to “about what you would expect” (7 of 13), with the others averaging to “harder than you would expect.” Most community-based services averaged to “harder than you would expect” (6 of 10), with the remainder averaging to “about what you would expect.” When comparing the average scores for all 23 services, the most difficult services to obtain statewide are 1) respite care, 2) transportation assistance, 3) recreation opportunities, 4) planning for transition to adulthood, with a tie at 5) mental health/behavioral services and summer/after-school care. Five of these are community-based services. These findings

are similar to those for the county-level provider survey in that respite, summer/after-school care, and transportation were difficult to obtain (available in less than 90 percent of counties – within or in adjoining). Table 24 below displays these findings.

Table 24. Level of Difficulty/Burden in Obtaining Selected Services for CSHCN, Statewide, 2009

| Service | Harder than you would expect (1), frequency (%) | About what you would expect (2), frequency (%) | Easier than you would expect (3), frequency (%) | Mean Level of Difficulty |
|---|---|--|---|--------------------------|
| Health Services | | | | |
| Dental | 22 (32.8) | 37 (55.2) | 8 (11.9) | 1.79 |
| Developmental screening | 15 (22.4) | 50 (74.6) | 2 (3) | 1.81 |
| Emergency care | 24 (35.8) | 35 (52.2) | 8 (11.9) | 1.76 |
| Hearing/hearing aids | 27 (40.3) | 35 (52.2) | 5 (7.5) | 1.67 |
| <i>Mental Health/Behavioral^α</i> | 43 (64.2) | 24 (35.8) | 0 | 1.36 |
| Nutrition | 28 (41.8) | 31 (46.3) | 8 (11.9) | 1.70 |
| Occupational therapy | 36 (53.7) | 26 (38.8) | 5 (7.5) | 1.54 |
| Physical therapy | 31 (46.3) | 29 (43.3) | 7 (10.4) | 1.64 |
| Primary care | 1 (1.5) | 49 (73.1) | 17 (25.4) | 2.24 |
| Special equipment or braces | 34 (50.7) | 29 (43.3) | 4 (6) | 1.55 |
| Specialty care | 40 (59.7) | 23 (34.3) | 4 (6) | 1.46 |
| Speech therapy | 38 (56.7) | 24 (35.8) | 5 (7.5) | 1.51 |
| Vision/eyeglasses | 17 (25.4) | 46 (68.7) | 4 (6) | 1.81 |
| Community-based Services | | | | |
| Care coordination | 13 (19.4) | 48 (71.6) | 6 (9) | 1.90 |
| Child care facilities/day care | 30 (44.8) | 32 (47.8) | 5 (7.5) | 1.63 |
| Early intervention | 2 (3) | 52 (77.6) | 13 (19.4) | 2.16 |
| Education services | 3 (4.5) | 52 (77.6) | 12 (17.9) | 2.13 |
| Family support | 39 (58.2) | 26 (38.8) | 2 (3) | 1.45 |
| <i>Planning for transition to adulthood^α</i> | 49 (73.1) | 17 (25.4) | 1 (1.5) | 1.28 |
| <i>Recreation opportunities^α</i> | 51 (76.1) | 14 (20.9) | 2 (3) | 1.27 |
| <i>Respite care^α</i> | 61 (91) | 6 (9) | 0 | 1.09 |
| <i>Summer/after-school care^α</i> | 43 (64.2) | 24 (35.8) | 0 | 1.36 |
| <i>Transportation assistance^α</i> | 54 (80.6) | 13 (19.4) | 0 | 1.19 |

Source: Key Informant Interviews conducted for all 67 Alabama counties

^α Italicized services designate top 5 most difficult services to obtain

Stratifying these results by geographic region and Black Belt designation revealed differences in assessment of difficulty to obtain these services. For Rural North counties, six of 13 health services and four of 10 community-based services were ranked as “about what you would expect.” The rest were ranked as “harder than you would expect.” For Rural South counties, five of 13 health services and three of 10 community-based services were ranked “about what you would expect,” while the rest were “harder than you would expect.” Urban counties fared better in that no health services and only four of 10 community services rated “harder than you would expect.” All other services ranked “about what you would expect” in the Urban counties. In counties designated as Black Belt, three of 13 health services and three of 10 community-based services were rated “about what you would expect,” while all other services were rated as “harder than you would expect.” Of interest, for both

Rural North and Rural South counties, four of the six top most-difficult services to obtain were community-based services. Due to the small numbers of Urban counties, there were ties in stratifying down; however, six of the seven top most-difficult services to obtain were community-based services. Black Belt counties also had several ties related to the most difficult services to obtain, but six of 12 were community-based services. This means that Black Belt counties have equal difficulties obtaining both health and community-based services, but other designations tend to have the most difficulty obtaining community-based services. In those areas that reported specific health services as “harder than you would expect,” the services were mental health/behavioral, occupational therapy, physical therapy, special equipment/braces, specialty care, and speech therapy. Table 25 below displays results for services that were rated “harder than you would expect” by geographic region and Black Belt designation.

Table 25. Health and community-based services rated by key informants as “harder than you would expect” to obtain for CYSHCN and their families, 2009

| Designation | “Harder than you would expect” | | |
|--------------------|--|---|---------------------------|
| | Health Services | Community-based Services | Total (of 23 services) |
| Statewide | <ul style="list-style-type: none"> • Mental health/behavioral • Occupational therapy • Physical therapy • Special equipment or braces • Specialty care • Speech therapy | <ul style="list-style-type: none"> • Family support • Respite care • Planning for transition to adulthood • Recreation opportunities • Summer/after-school care • Transportation assistance | 12 |
| Rural North | <ul style="list-style-type: none"> • Emergency care • Hearing/hearing aids • Mental health/behavioral • Occupational therapy • Physical therapy • Special equipment or braces • Specialty care • Speech therapy | <ul style="list-style-type: none"> • Child care facilities/day care • Family support • Planning for transition to adulthood • Recreation opportunities • Respite care • Summer/after-school care • Transportation assistance | 15 |
| Rural South | <ul style="list-style-type: none"> • Hearing/hearing aids • Mental health/behavioral • Nutrition • Occupational therapy • Physical therapy • Special equipment or braces • Specialty care • Speech therapy | <ul style="list-style-type: none"> • Child care facilities/day care • Family support • Planning for transition to adulthood • Recreation opportunities • Respite care • Summer/after-school care • Transportation assistance | 15 |
| Urban | | <ul style="list-style-type: none"> • Planning for transition to adulthood • Respite care • Summer/after-school care • Transportation assistance | 4 |
| Black Belt | <ul style="list-style-type: none"> • Dental • Emergency care • Hearing/hearing aids • Mental health/behavioral • Nutrition • Occupational therapy • Physical therapy • Special equipment or braces • Specialty care • Speech therapy | <ul style="list-style-type: none"> • Child care facilities/day care • Family support • Planning for transition to adulthood • Recreation opportunities • Respite care • Summer/after-school care • Transportation assistance | 17 |

Greatest Needs

Key informants were asked to consider all of the needs in the county in light of how they had rated the difficulty or burden in obtaining services. They were then asked to identify the three greatest needs in the county. Transportation ranked in the top three greatest needs statewide and for all

stratifications. Therapies (physical therapy, occupational therapy, speech therapy, and nutrition) ranked in the top three statewide and for all stratifications except for Urban counties. Specialty care was a greatest need for Rural South counties and those designated as Black Belt. Although more of the community-based services were ranked as “harder than you would expect” to obtain, selected health services were predominantly in the top three greatest needs statewide and for all designations except Urban. Though ties within the smaller number of Urban counties made it somewhat difficult to identify three needs, six of the seven top greatest needs were community-based services. Perhaps once general health service needs are met, key informants begin to consider the community-based supports that are adjunctive to them. Although transportation assistance is considered a community-based service support, its importance across all stratifications is not unexpected given the criticality of getting to services statewide. Table 26 below summarizes these findings.

Table 26. Greatest needs by geographic area and Black Belt designation, in rank order, 2009

| Statewide | Rural North | Rural South | Urban | Black Belt |
|---|---|---|--|---|
| Transportation | Transportation | Transportation | Respite <i>and</i> Transportation | Transportation |
| Respite | Respite | Therapies (PT, OT, SP, nutrition) | Child care <i>and</i> Mental health/behavioral | Therapies (PT, OT, SP, nutrition) |
| Therapies (PT, OT, SP, nutrition) | Child care <i>and</i> Therapies (PT, OT, SP, nutrition) | Specialty care | Family support and Summer/after-school care <i>and</i> Transition | Specialty care |

Source: Key Informant Interviews

Effectiveness of the Overall System of Care for CYSHCN and their Families

Key informants were asked to rate the overall effectiveness of the system of care in the county in meeting the needs of CYSHCN and their families. Choices were again along a Likert scale including “excellent,” “above average,” “average,” “below average,” and “very poor.” Combining results statewide, the overall system of care in Alabama was rated “average.” Examining these ratings by geographic region and Black Belt designation revealed differences in effectiveness. Rural North, Rural South, and Black Belt counties rated “below average” overall, while Urban counties rated “average.”

Youth Surveys

Summary: Alabama youth with special health care needs are typically insured and have a source for primary care. There is room for improvement related to transition and health care independence. Youth who received help completing the survey were less likely to report selected future plans than were those who did not receive help. Severity of condition only partially explains these differences.

The survey was adapted from a tool created by the North Carolina Title V Program, Specialized Services Unit of the Division of Public Health. Original publication was possible through a grant from the CDC, Division of Birth Defects, Child Development, Disability, and Health Branch. It was utilized as a portion of the North Carolina 1999 needs assessment process. Permission was obtained to modify the survey for use in Alabama as a part of the 2004 needs assessment. This tool was again modified for use in the 2009 needs assessment. Modifications also included mirroring questions from the National Survey of Children with Special Health Care Needs (NSCSHCN). The instrument consists of 25 questions, with both open-ended and check box answers possible. The survey targets youth with SHCN (ages 12-25 years) and includes questions related to basic demographics, condition or disability, insurance, health status, impact of condition or disability, school status, transition, social activity, future plans, informational needs, and whether help was obtained in completing the survey.

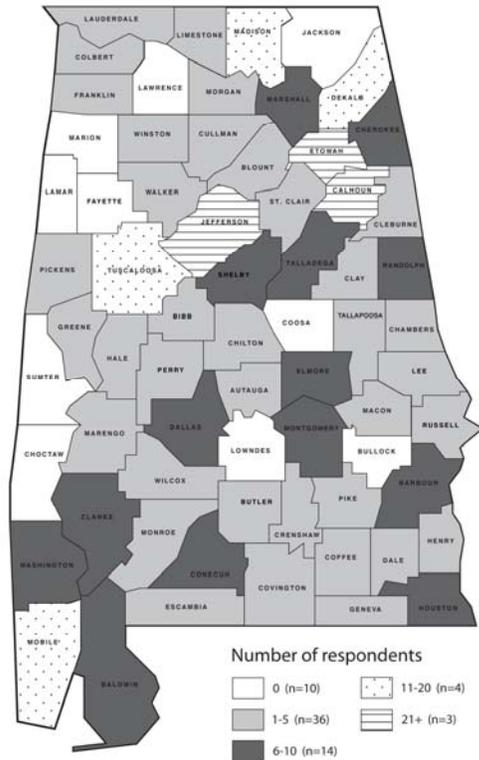
There were 336 surveys submitted, combining electronic and hard copy versions and English and Spanish responses (response rate 37.2 percent). This is an increase over the 229 responses from 2004 (35 percent response rate). Methodology for dissemination was primarily passive in that surveys were placed in strategic locations likely to be frequented by youth with SHCN, but also included postcards and newsletter awareness tools and electronic outreach methods including email, listservs, links on websites, and Facebook. Most surveys were completed in English and in hard copy.

Results follow, presented in broad categories. In general, findings indicate that responses from these youth were quite similar to those that might be expected from typically developing peers in terms of social activity choices, future plans, and perceived health status. This group appears to be insured, to have a source of routine primary care, to be currently in high school, to live in parents' homes, and to be more likely to receive Medicaid benefits. Youth who completed the survey without help from any outside source were more likely to have future plans that included completing college, working for pay, getting married, having children, and living independently than were those who needed help completing the items. Although only five youth took the survey in Spanish, those who did were more likely to report future plans that included living with family. It was suggested that this may be as result of a cultural preference to live with family until marriage.

Demographics

Respondents were on average 18 years old and tended to be female (54.4 percent). Just over 62 percent were white, while about 30 percent were African American, 4 percent were Hispanic, and about 3 percent were other races (multi-race, American Indian, etc.). The vast majority were currently in school and continued to live in their parents' homes. Of the 289 youth who answered the question related to whether they received help in completing the survey, 142 (49.1 percent) indicated that they had received help of some kind. This help may have included assistance reading the questions, writing down the answers given by the youth, translating the questions into the youth's language, or answering the questions on behalf of the youth. If help was received at all, the most common form was for someone to complete the survey on behalf of the youth or reading the questions to the youth. Responses were received from youth living in 57 of Alabama's 67 counties. Figure 4 below displays responses by county.

Figure 4. Youth survey respondents by county



Insurance

Within the group of respondents, 9.4 percent reported that they had no insurance. For those who reported no insurance, all but five were over 18 years of age. For those who indicated they had insurance, 51.6 percent reported that they had Medicaid, 36.7 percent reported private, 6.5 percent reported All-Kids (State Children’s Health Insurance Program), and the remainder reported other insurance. These findings are similar to the 2004 findings.

Health Status, Impact of Condition, and Health-Related Issues

A list of 20 conditions or disabilities was included. Respondents were to indicate which, if any, of the conditions applied to them. Commonly reported conditions were epilepsy, cerebral palsy, orthopedic conditions, deafness/hearing impairment, blindness/vision impairment, learning disabilities, attention deficit disorder, mental health problems, respiratory conditions, and speech/language disorders.

Most youth indicated that they had a source of primary care, typically a physician’s office, with only 6.1 percent indicating that they had no source of routine primary care. In responding to an item related to perceived health status, 75.2 percent of youth reported that their health was “good” or “excellent.” These findings were similar to those reported in the 2004 needs assessment. Youth were also asked to comment on how often their health condition affected their ability “to do things.” Of those who responded, 62.9 percent of youth reported at least “sometimes” (includes “sometimes,” “frequently,” and “always”). Youth were asked to rate the severity of the difficulties caused by their special health care needs. Almost 40 percent reported “moderate,” with 26.3 percent reporting “minor” and 20.1 percent reporting “severe.” Just over 16 percent indicated that they did not know.

Transition and Health Care Independence

Several questions addressed health care independence. Just over 44 percent of youth indicated that their health care provider had talked with them about their health care needs as they become adults. Given the age range of survey respondents (14-20 years), this is a somewhat low percentage. About 51 percent of youth felt that their health care provider “frequently” or “always” encouraged them to take responsibility for their health care needs. Of those youth who had a visit during the year prior to the survey and indicated an answer, 60 percent said that they had *not* been given a chance to speak to the health care provider privately. This could potentially impede questions related to sensitive issues that may become important during adolescence. Finally, almost 45 percent reported that their health care provider “frequently” or “always” helped them feel involved or included in their health care decisions. Again, this is a somewhat low percentage give the age range of survey participants.

Social Activity

Several survey questions related to social activity. Of those youth who responded, almost 80 percent stated that they spend time doing things with people outside their homes “sometimes” or “a lot.” A list of 17 social activities was included and youth were to indicate which, if any, they participated in. In general, the three most commonly reported social activities were “watching television,” “listening to music,” and “computer.” Across all severity ratings, the top six activities were similar. There were some differences noted based on whether youth received help completing the survey, especially those where someone else had completed the survey on their behalf. Though the percentages differed, the most commonly reported activities were similar across all groups. These most common activities may be described as somewhat sedentary, and results are similar to those seen in the 2004 responses.

Future Plans

Youth were asked to consider a list of 10 potential future plans (choices for “don’t know,” “none of these apply to me,” and “other” were also possible). In general, the most commonly reported plans included “working for pay,” “living independently,” “completing high school,” “completing graduate school or professional school,” and “marrying.” Responses were stratified based on whether the youth received help completing the survey and based on severity. In the 2004 needs assessment, CRS also stratified responses to this question based on whether the youth received help completing the survey. Severity questions were not included in the 2004 iteration of the survey. As seen in 2004, clear differences were noted for future plan activities based on whether the youth received help completing the survey. Youth who received help completing the survey were less likely to report these future plans, especially if the help was in the form of someone else completing the survey on the youth’s behalf. A similar trend was demonstrated for those who rated the impact of their condition as “severe.” The trend for severity may be as expected, and when help was given in the form of someone else completing the survey on the youth’s behalf, perhaps this is a proxy for severity. For this question, 24 percent of respondents had a severity rating of “severe” and 22 percent indicated they had received help in the form of “someone else completing the survey on the youth’s behalf.” It may be that youth with severity ratings of “severe” and those who received help in the form of “someone else completing the survey on the youth’s behalf” are the same respondents. However, the lower numbers for youth who received any other help at all – excluding the category who received help in the from of someone else completing on the youth’s behalf – are somewhat puzzling given that the help may have been simply to write down the answers the youth provided or to assist the youth by reading the questions. Reasons for these significant variations may include: those who received help may be youth with more severe conditions; youth may think more independently if they are able to answer the survey without help; or youth may have different plans

for themselves than those expressed by those who helped them complete the survey. This may indicate a need to educate and empower youth and their families about the future. Table 27 and 28 below illustrate these differences.

Table 27. Future plans reported by youth with special health care needs, by “received help”

| Future Plan | “Yes,” Did Not Receive Help (%) | “Yes,” Received Any Other Help* (%) | “Yes,” Someone Else Completed on Youth’s Behalf (%) |
|--|--|---|---|
| Living independently | 59.4 | 47.8 | 40.7 |
| Marrying | 58.7 | 53.2 | 29.6 |
| Working for pay | 67.1 | 47.8 | 48.1 |
| Completing high school | 49.7 | 41.4 | 50.0 |
| Completing graduate or professional school | 58.0 | 48.7 | 25.9 |

* Does not include “someone else completed on youth’s behalf”

Table 28. Future plans reported by youth with special health care needs, by severity

| Future Plan | “Yes,” Minor or Moderate (%) | “Yes,” Severe (%) |
|--|------------------------------------|-------------------------|
| Living independently | 61.3 | 26.3 |
| Marrying | 57.9 | 24.6 |
| Working for pay | 66.0 | 35.1 |
| Completing high school | 59.1 | 31.6 |
| Completing graduate or professional school | 56.4 | 24.6 |

Information Needs

Youth were asked to consider a list of topics and to indicate any for which they would like to receive more information. The top six requests were job/careers, condition or disability, further education and training, healthy behaviors, successful persons living with disability, and insurance/“how to pay for my health care.”

Family Surveys

Summary: Alabama families of CYSHCN typically report insurance for their children and most indicate that their child has a personal health care provider. Most reported that they had felt like a partner in their child's health care and that he or she had been screened regularly for special health care needs and developmental delays, though some potential trends were noted based on ethnicity. There is room for improvement related to health care transitions and independence, though the average age of respondents' children is quite young. Future planning activities were similar to the future plans indicated by youth in the youth survey, though there were differences noted based on severity. Although overall indication of need for community-based services is less, families report greater percentages of unmet need for those services. There are differences in barriers to receiving services based on geographic area and Black Belt designation.

The survey was created based on research of tools utilized in other settings and mirrored questions from the county-level provider survey and the National Survey of Children with Special Health Care Needs (NSCSHCN), 2005/06. The tool was piloted by CRS Local Parent Consultants and two to three Local Parent Advisory Committee members in each district. The instrument consists of 26 questions, with both open-ended and check box answers possible. The survey targets families who have CYSHCN and includes questions related to basic demographics and information on need for, receipt of, and satisfaction with health and community-based services; on perceived barriers to care; on medical home; on transition services; and on informational needs.

There were 1,103 surveys submitted, combining English and Spanish responses and both electronic and paper copy submissions (response rate 39.3 percent). Methodology for dissemination was primarily passive in that surveys were placed in strategic locations likely to be frequented by families of CYSHCN, but also included postcards and newsletter awareness tools and electronic outreach methods including email, listservs, links on websites, and Facebook. Most surveys were completed in English and in hard copy.

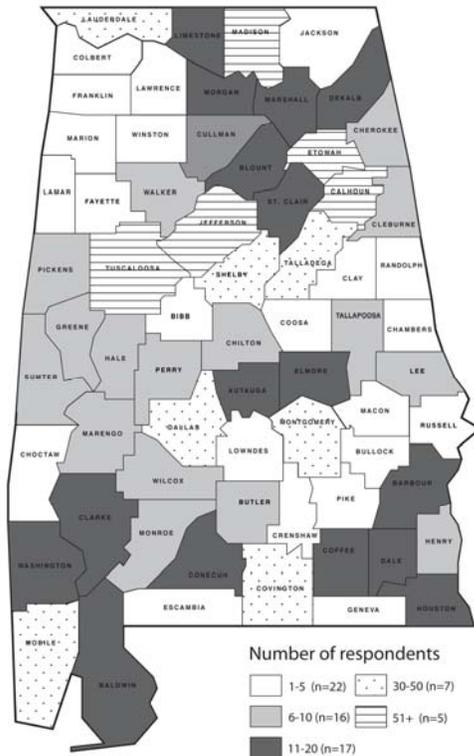
Results follow, presented in broad categories. There were some differences noted between groups who took the survey in Spanish and those who took it in English, but these are discussed simply as trends since only 32 respondents took the survey in Spanish.

Demographics

Respondents typically indicated that they had one CYSHCN in the family, tended to be the parent, and were most often female (87 percent). The average age of the CYSHCN for those who took the survey in English was 11 years, while it was lower – 9 years – for those who took the survey in Spanish. Just over 61 percent were white, while about 34 percent were African American, 3 percent were Hispanic, and about 2 percent were other races (Asian, American Indian, etc.). This racial/ethnic distribution is similar to that observed in the youth survey. For respondents who took the survey in English, 86.5 percent had at least a high school education. Of those, 56.5 had some college or a college degree. For those who took the survey in Spanish, a lower percentage – 46.2

percent – had at least a high school education. Of those, 30.8 had some college or a college degree. In both groups, most respondents were married. There were responses from at least one family living in all of Alabama’s 67 counties. Figure 5 below displays response by county.

Figure 5. Family survey respondents by county



Insurance

Within the group of respondents, 9.4 percent (3) of those who took the survey in Spanish and 3.5 percent (35) of those who took it in English reported that their CYSHCN had no insurance. Again, only 32 respondents took the survey in Spanish, but this difference bears consideration. Overall, 3.7 percent of respondents reported that their CYSHCN was uninsured. Combining the groups, of those who indicated that their CYSHCN had insurance, 63.4 percent reported Medicaid, 35.2 percent reported private, 6.2 percent reported All-Kids (State Children’s Health Insurance Program), and the remainder reported other insurance. These findings are similar to the youth survey findings except youth survey respondents reported slightly higher uninsured percentages and slightly lower Medicaid.

Impact of Condition

In both respondent groups, the majority of families rated the severity of difficulties caused by the special health care need as “moderate.” This is similar to the findings from the youth survey.

Health and Community-based Services

The same list of health and community-based services utilized in the county-level provider survey and key informant interviews was presented to families. Respondents were asked to indicate which services their CYSHCN had needed during the previous 12 months. For those services that were needed, families were asked to indicate whether they actually received the service. Respondents

were also asked about satisfaction with services received, but those results are not presented in this document. There was a large amount of missing data in this section of the survey. Even though the survey tool was piloted and modifications were made as indicated, the CRS small leadership team believes retrospectively that this section was awkward, especially in hard copy. The electronic version of the survey facilitated better flow for these questions; however, the section still seems daunting. Many respondents either skipped the section entirely or provided inconsistent responses (i.e., responding that their CYSHCN received a service when they had not indicated a need for it, or failing to respond whether their CYSHCN received a needed service.) Resource limitations, as well as respondents not indicating they would be receptive to a call for further information, prevented follow-up to clarify responses. In the future, CRS will modify the way these questions are presented.

The large amount of missing data prevented any further stratification by geographic area or Black Belt designation. There is little difference in the percentages of identified need for services by region; however, there are regional differences in non-response rates. It appears that respondents from Urban areas tended to have less missing data than did those in the Rural North and Rural South areas. Therefore, the Urban data may be over-represented or over-counted in the sample. It would not be a sound research practice to either exclude the missing data or to count it equally in the “yes” and “no” columns for receipt of service. To exclude this data in its entirety would skew the results and percentages and there is no way to accurately determine how to divide the non-response between “yes, received” and “no, did not receive.” There is definitely bias in the sample based on where the respondents live geographically; however, the cause cannot be determined. The CRS needs assessment small leadership team has posited that perhaps differences in educational and literacy levels between urban and rural areas may explain some portion of the observed differences. Regardless, only statewide information can be presented in a reliable and valid format.

The most commonly reported service needs were for primary care, dental services, educational services, vision care/eyeglasses, and primary care. This is not surprising for children and youth in general. For those services, most respondents indicated that their CYSHCN received the needed service. Non-receipt ranged from 2.4 percent for primary care to 9.3 percent for educational services. Other services may have been indicated as a need by a lower percentage of respondents, but were striking in terms of non-receipt. For example, only a little more than 20 percent of respondents indicated that they had needed summer or after-school care for their CYSHCN, but more than 42 percent did not receive it. This means that although only 20 percent of respondents reported this need, more than 42 percent of them were unable to get the service. For seven services, 20 percent or more of those who indicated a need were unable to obtain the service. All seven of these services are community-based services (of the 10 total community-based services). There were no health services that yielded this high of a percentage of non-receipt of service – i.e., unmet need. The highest percentages for health services were reported for the following services in percent of unmet need order: mental health/behavioral, occupational therapy, speech therapy, and nutrition. The percent of unmet need ranged from 12.4 percent for nutrition to 16.3 percent for mental health/behavioral services. Table 29 below summarizes these results.

Table 29. Percentage of Families Reporting Non-Receipt of Needed Services, Statewide, 2009

| Service | Indicated need for service (%) | Indicated need for service but did not receive ^a (%) |
|--------------------------------------|--------------------------------|---|
| Health Services | | |
| Dental | 57.0 | 9.2 |
| Developmental screening | 35.0 | 9.6 |
| Emergency care | 27.9 | 2.0 |
| Hearing/hearing aids | 23.9 | 7.8 |
| Mental health/behavioral | 27.0 | 16.3 |
| Nutrition | 26.4 | 12.4 |
| Occupational therapy | 38.3 | 14.6 |
| Physical therapy | 37.7 | 8.2 |
| Primary care | 61.9 | 2.4 |
| Special equipment or braces | 35.4 | 8.4 |
| Specialty care | 43.2 | 3.9 |
| Speech therapy | 39.3 | 12.8 |
| Vision/eyeglasses | 43.2 | 6.9 |
| Community-based Services | | |
| Care coordination | 16.8 | 18.9 |
| Child care facilities/day care | 19.0 | 32.0 |
| Early Intervention | 17.2 | 6.5 |
| Education services | 46.2 | 9.3 |
| Family support | 22.7 | 32.5 |
| Planning for transition to adulthood | 13.6 | 34.5 |
| Recreation opportunities | 22.9 | 35.1 |
| Respite care | 17.9 | 25.0 |
| Summer/after-school care | 20.2 | 42.1 |
| Transportation assistance | 20.9 | 23.2 |

Source: Alabama Family Survey

^a Missing data for this question ranged from 7.1% – 15.9%

Shaded services were needed but not received by 20% or more of family respondents

Barriers to Receiving Care

A list was provided of 15 potential barriers to receiving services that might be experienced by CYSHCN and their families. Respondents were asked to check any item that had posed a barrier for them over the previous 12 months. Responses were tabulated to obtain the number of respondents who identified the item as a barrier. Barriers were then ranked based on the percentage of respondents who identified the issue as a barrier for them and for their CYSHCN. In the event of a tie for both scores, the barriers were presented in the order in which they appeared in the survey. Barriers were ranked statewide and by geographic region and Black Belt designation.

Statewide Barriers

Overall, the most commonly reported barrier was that “insurance didn’t cover services.” More than a quarter of all families reported that they had experienced this barrier over the previous year. Almost this same amount had experienced the barrier “did not know where to go or who to see.” The top six

barriers were reported by at least 20 percent of respondents. Although only a small percentage of families reported needs for care coordination in the service needs section (see Table 29 above), the second most common barrier indicated was “did not know where to go/who to see.” CRS believes that these are comparable and perhaps families do not recognize what “care coordination” means or how it can assist them in navigating the system of care. A comparison of family and provider responses about barriers to care is presented in the last section of this chapter. Table 30 below presents the statewide results for barriers to care from the perspective of parents.

Table 30. Barriers to receiving services for CYSHCN, statewide, 2009

| Barrier | Percent indicated |
|--|--------------------------|
| 1. Insurance didn't cover services | 26.3 |
| 2. Did not know where to go/who to see | 24.8 |
| 3. Missed school days | 21.6 |
| 4. Transportation | 21.0 |
| 5. Can't afford co-pays and deductibles | 20.3 |
| 6. Services too expensive | 20.1 |
| 7. Waiting list for services too long | 18.8 |
| 8. Providers not available | 16.8 |
| 9. Work conflict – unable to take time off work | 16.1 |
| 10. Work conflict – can't afford to lose pay | 15.6 |
| 11. Hours/location of providers not convenient | 15.1 |
| 12. Lack of child care | 14.5 |
| 13. State policy or administrative barriers | 9.0 |
| 14. No insurance | 8.0 |
| 15. Language/ cultural barriers | 3.0 |

Source: Family Survey

Because some barriers were closely related, individual barriers were combined into themes. About 75 percent of respondents indicated that financial issues had been a barrier to their CYSHCN receiving services over the previous year. More than 50 percent reported that they had experienced work/school issues and provider/service issues. The final categories for theme are comprised of only one barrier, so they are represented by a somewhat smaller percentage of respondents. Table 31 below summarizes these results.

Table 31. Barriers to receiving services for CYSHCN and families by theme, statewide, 2009

| Barriers by Theme | Percent of respondents indicating barrier |
|--------------------------|--|
| Financial issues | 75 |
| Work/school issues | 53 |
| Provider/service issues | 51 |
| Care coordination issues | 25 |
| Transportation issues | 21 |
| Child care issues | 15 |
| Administration issues | 9 |
| Language/cultural issues | 3 |

Source: Family Survey

Barriers According to Geographic Area and Black Belt Designation

Responses were stratified according to geographic region and Black Belt designation. Data were compared between groups. Differences can be observed in the percent of families that indicated they had experienced a particular barrier based on these groupings.

The percentage differences between both the geographic regions and Black Belt designation are statistically significant for three barriers – “insurance didn’t cover services,” “services too expensive,” and “transportation.” Respondents from the Rural South and Black Belt were less likely to indicate “insurance didn’t cover services” than were respondents from other geographic regions or non-Black Belt counties. Respondents living in Urban and non-Black Belt counties were more likely to report “services too expensive” as a barrier than were those in the rural geographic regions or the Black Belt counties. As noted earlier, both rural geographic areas, especially Rural South, and Black Belt counties have higher percentages of children under age 21 years eligible for Medicaid. This may explain these differences to some degree given that medically necessary services are required to be provided under the EPSDT (Early Periodic Screening, Diagnosis, and Treatment) benefit and Alabama Medicaid does not impose cost-sharing requirements on its recipients. Also, families living in the Rural South and Black Belt counties were more likely to report “transportation” as a barrier than were those in other geographic regions or non-Black Belt counties.

In addition to the ones above, the percentage differences between the geographic regions are also statistically significant for “state policy or administrative barriers.” Respondents living in Urban areas were more likely to report this barrier than were those living in either the Rural North or Rural South.

The percentage difference between Black Belt and non-Black Belt counties is also statistically significant for six barriers in addition to the ones mentioned above. They are “did not know where to go or who to see,” “can’t afford co-pays and deductibles,” “waiting list for services too long,” “providers not available,” “work conflict – unable to take time off work,” and “work conflict – can’t afford to lose pay.” For example, respondents from Black Belt counties were less likely to report “can’t afford co-pays and deductibles” as a barrier than were those living in non-Black Belt counties. This finding may again be explained by the comment about the lack of cost-sharing requirements in Alabama Medicaid, as mentioned above. As previously noted, about 52 percent of all children under age 21 years in Black Belt counties are eligible for Medicaid compared with about 40 percent in non-Black Belt counties. Table 32 below displays these results by geographic region and Black Belt designation.

Table 32. Barriers to receiving services for CYSHCN, by geographic region and Black Belt designation, 2009

| Barrier | Percent indicated | | | | |
|---|-------------------|-------------|-------|------------|----------------|
| | Rural North | Rural South | Urban | Black Belt | Non-Black Belt |
| Insurance didn't cover services* ^B | 15.9 | 9.4 | 17.2 | 7.4 | 16.5 |
| Did not know where to go/who to see ^B | 13.6 | 13.6 | 14.2 | 7.4 | 15.2 |
| Missed school days | 10.7 | 12.8 | 12.9 | 11.1 | 12.6 |
| Transportation* ^B | 8.9 | 18.3 | 9.6 | 18.5 | 10.2 |
| Can't afford co-pays and deductibles ^B | 9.3 | 8.9 | 13.2 | 5.6 | 12.5 |
| Services too expensive* ^B | 8.9 | 7.7 | 14.0 | 3.1 | 13.0 |
| Waiting list for services too long ^B | 7.5 | 9.8 | 12.1 | 6.2 | 11.4 |
| Providers not available ^B | 10.3 | 6.8 | 11.0 | 4.9 | 10.8 |
| Work conflict – unable to take time off work ^B | 10.3 | 7.2 | 10.0 | 3.7 | 10.5 |
| Work conflict – can't afford to lose pay ^B | 8.4 | 6.4 | 9.5 | 4.3 | 9.3 |
| Hours/location of providers not convenient | 11.7 | 8.5 | 7.8 | 6.2 | 9.3 |
| Lack of child care | 6.5 | 6.4 | 8.7 | 5.6 | 8.1 |
| State policy or administrative barriers* | 2.8 | 4.3 | 7.0 | 3.1 | 5.9 |
| No insurance | 3.3 | 4.3 | 4.3 | 4.9 | 3.9 |
| Language/ cultural barriers | .5 | 2.1 | 1.7 | 1.2 | 1.6 |

Source: Family Survey

* Geographic differences significant at $p < .05$ by Pearson's Chi-Square

^B Black Belt differences significant at $p < .05$ by Pearson's Chi-Square

Using the percentages of respondents who identified each issue as a barrier, the top five barriers were ranked for each geographic region and for Black Belt designation. "Insurance didn't cover services," "missed school days," and "did not know where to go or who to see" ranked in the top five for all geographic regions. Beyond that, differences in barriers were noted. For example, "services too expensive" and "can't afford co-pays and deductibles" were top five barriers in the Urban region, but were ranked slightly lower in the Rural North and Rural South regions. Table 33 below summarizes rankings based on geographic region.

Table 33. Top five barriers to receiving services for CYSHCN, by geographic region, 2009

| Rank | Rural North | Rural South | Urban |
|------|---|-------------------------------------|--------------------------------------|
| 1 | Insurance didn't cover services | Transportation | Insurance didn't cover services |
| 2 | Did not know where to go/who to see | Did not know where to go/who to see | Did not know where to go/who to see |
| 3 | Hours/location of providers not convenient | Missed school days | Services too expensive |
| 4 | Missed school days | Waiting list for services too long | Can't afford co-pays and deductibles |
| 5 | Providers not available <i>and</i> Work conflict – unable to take time off work | Insurance didn't cover services | Missed school days |

Source: Family Survey

Comparing differences in rankings by Black Belt designation also reveals differences. “Insurance didn’t cover services,” “can’t afford co-pays and deductibles,” “missed school days,” and “did not know where to go or who to see” ranked in the top five for both designations. Though ties were evident due to the small number of counties in the Black Belt region, “transportation,” “waiting lists,” “hours/locations of providers not convenient,” and “lack of childcare” were all in the top five for Black Belt. “Services too expensive” was ranked in the top five for non-Black Belt counties. Table 34 below summarizes the rankings by Black Belt designation.

Table 34. Top five barriers to receiving services for CYSHCN, by Black Belt designation, 2009

| Rank | Black Belt | Non-Black Belt |
|------|--|--------------------------------------|
| 1 | Transportation | Insurance didn’t cover services |
| 2 | Missed school days | Did not know where to go/who to see |
| 3 | Insurance didn’t cover services <i>and</i> Did not know where to go/who to see | Services too expensive |
| 4 | Waiting list for services too long <i>and</i> Hours/location of providers not convenient | Missed school days |
| 5 | Can’t afford co-pays and deductibles <i>and</i> Lack of child care | Can’t afford co-pays and deductibles |

Source: Family Survey

Medical Home and Continuous Screening

The majority of respondents in both groups indicated that their CYSHCN had a person or persons that they considered a personal doctor or nurse, though the percentages were higher in the group that took the survey in English (87.6 percent versus 66.6 percent). Respondents were asked whether the child’s main health care provider had helped them feel like a partner in health care over the previous 12 months. For the group that took the survey in English, almost 78 percent said that this was “usually” or “always” the case. For those who took the survey in Spanish, only 23 percent reported these same findings. Of the respondents who took the survey in Spanish, 96 percent indicated they had needed an interpreter. Of those, almost 55 percent said they were able to get an interpreter other than a family member to help them speak with the health care provider. Of those who took the survey in English, almost 70 percent indicated that their child had been screened regularly for special health needs and developmental delays. For those who took the survey in Spanish, this was indicated by only about 17 percent. Again, only 32 respondents took the survey in Spanish and this trend toward lower partnership with health providers and less consistent screening for health needs and developmental delays may be somewhat indicative of a language barrier; however, it is still important to consider in program planning.

Transition Services and Planning for the Future

Two questions dealt specifically with health care transition. About 59 percent of respondents (similar for both groups) indicated that their child’s doctor or health provider had ***not*** talked with

them about the child’s health care needs as he or she becomes an adult. Only about 41 percent reported that the child’s health providers had encouraged him or her to take responsibility for his or her health care. The young average age of the respondents’ CYSHCN (11 years and 9 years for English and Spanish groups, respectively) may have impacted these results.

As in the youth survey, the family survey included a list of potential future plans. Families were asked to consider their oldest CYSHCN in responding whether they had begun to make plans for any of the items. There was a large amount of missing data for this question, so the results must be interpreted with caution. In general, the most commonly reported items that families had begun planning for included “completing high school/GED,” “completing college (includes advance degrees and technical school),” “social relationships (friends, romantic),” “living with family,” and “working for pay.” Again, the young average age of CYSHCN may have impacted these results somewhat.

Survey responses for this question were stratified based on severity. Those respondents who classified the difficulties caused by their child’s special health care need as “severe” had different responses when compared with those who classified the difficulties as “minor” or “moderate.” This is not entirely unexpected. However, this does not mean that families do not include these activities as possibilities in the child’s future. It simply means that they have not yet begun to plan for them. In addition to severity, the young average age may also explain some of the observed differences. Table 35 below displays these findings.

Table 35. Future planning reported by families of CYSHCN, by severity

| Planning for the Future | “Yes”, Minor or Moderate (%) | “Yes”, Severe (%) |
|--|------------------------------------|-------------------------|
| Living with family | 28.8 | 45.5 |
| Social relationships (friends, romantic) | 39.8 | 28.0 |
| Working for pay | 38.8 | 23.1 |
| Completing high school | 48.6 | 37.1 |
| Completing college | 15.1 | 6.8 |

Although a direct comparison between the questions related to future plans and planning cannot be made between the family and youth surveys, an approximation yields interesting results that warrant consideration. Caution must be taken in interpreting trends due to three issues. First, there is a large amount of missing data for this question on the family survey. Second, the youth survey respondents are older (average age 18 years) than are those CYSHCN about whom family survey respondents are considering the question – average age 9 years for Spanish and 11 years for English. Third, the youth survey asks the youth specifically if his or her future plans include any of the activities while the family survey asks families whether they have begun to make plans for any of the activities. With those important caveats clear, interesting trends can be seen based on severity rating. In general, though youth plans may include some of the typical future plans, in many cases their families have not yet begun to plan for those activities. This difference is exacerbated for those with difficulty levels rated “severe” by their families, but is still present even for those rated as “minor” or “moderate.” As would be expected, for those future plans that are most immediate (living with family and completing high school), the differences are not as pronounced. Table 36 below illustrates these findings for some of the more common responses.

Table 36. Future plans and planning reported by youth with special health care needs and their families, by severity

| Future Plan/Planning for the Future | Youth Survey “Yes”, Minor or Moderate (%) | Family Survey, “Yes”, Minor or Moderate (%) |
|-------------------------------------|--|--|
| Living independently | 61.3 | 29.8 |
| Living with family | 26.5 | 28.8 |
| Marrying/social relationships | 57.9 | 39.8 |
| Working for pay | 66.0 | 38.8 |
| Completing high school | 59.1 | 48.6 |
| Completing college | 56.4 | 15.1 |

Information Needs

Families were asked to consider a list of topics and to indicate any about which they would like to receive more information. The top requests for both groups included child’s condition or disability, recreational activities, successful persons living with condition/disability, healthy behaviors, and jobs/careers.

Focus Groups (Family, Youth, and Key State Stakeholders)

Summary: Families, youth, and key State stakeholders identified needs and barriers that were similar to those noted in the family, youth, and county-level provider surveys.

A discussion guide for the English, Hispanic, youth, and key state-level stakeholders focus groups was adapted from the format suggested in FOCUS on Children Community Planning Manual: Needs Assessment and Health Planning for Children, including Children with Special Health Care Needs (October 1996; published jointly by the University of Illinois at Chicago Division of Specialized Care for Children and the Illinois Department of Public Health through an MCHB-funded grant). A script was drafted for use in all forums, with a translation in Spanish and modifications for appropriateness for youth. The script was modified from that used in both the 1999 and 2004 needs assessment cycles, with minor updates to capture current issues and trends. An optional demographic sheet was available at the family and youth focus groups, to be utilized to better describe participants and the CYSHCN for whom they provided care.

Family and youth focus group participants were recruited to provide a broad representation across socioeconomic, geographic, and disability-type variables as well as to reach out to families and youth not enrolled in CRS. Key State stakeholders were selected by the smaller CRS needs assessment leadership team.

Youth

The youth focus group was conducted in a Montgomery suburb and included seven males and five females ranging in age from 14 to 20 years. Based on self identification, there were four Caucasian and eight African American youth. Most were still in high school, but several were attending college. The primary health conditions identified were seizures, cerebral palsy, cleft lip, asthma,

Asperger's syndrome, and ADHD. The severity of disability was rated as "moderate" by five youth and "severe" by the remaining four.

Family

A total of four family focus groups were held in Huntsville, Tuscaloosa, Jackson, and Birmingham. The Birmingham focus group had entirely Hispanic participants and differed somewhat from the other focus groups in terms of lower participant educational levels. The participants identified themselves as mothers (26), fathers (four), and grandparents (two) of CYSHCN. Based on self identification, there were 16 Caucasian, eight Latino/Hispanic, and seven African American participants. Participant educational levels were less than high-school (seven), high-school diploma/GED (seven), some college/associate degree/vocational training (11) and other (three). The ages of the CYSHCN for which they provided care ranged from 5 to 20 years, with a mean age of 10 years and the most commonly listed age at 17 years of age. The primary health conditions/disabilities of their children included cerebral palsy, autism, Down syndrome, ADD/ADHD, spina bifida, juvenile rheumatoid arthritis, hearing impairment, epilepsy, cleft lip and palate, learning disability, cystic fibrosis, brain damage, shaken baby syndrome, Crohn's disease, eating disabilities, and hydrocephalus. Participants rated the severity of their CYSHCN's condition/disability as "minor" (five), "moderate" (17), and "severe" (11).

Key State Stakeholders

Representatives were invited from the following entities: Alabama SCHIP, Family Voices of Alabama, Children's Health System, CSHCN Director, LEND program, Alabama Disabilities Advocacy Program, Alabama Medicaid Agency, Title V Director, Vocational Rehabilitation Service-Deaf/Blind Services, Alabama's Early Intervention System, United Cerebral Palsy, Alabama Lifespan Respite Resource Network, Alabama Chapter of American Academy of Pediatrics, Pediatric Pulmonary Center, Department of Mental Health-Office of Children's Services, Public Health-Office of Minority Health, State Department of Education-Special Education, and Voices for Alabama's Children.

Families and youth commented on several areas of concern related to the service system for CYSHCN in Alabama. Responses from the English and Spanish family forums were quite similar except for increased reporting of needs related to language barriers, acculturation, and difficulty locating resources for their children due to limitations in language, education, and computer skills. Youth responses tended to be more focused on independent living skills, social issues, and successful transition to adulthood. Key State stakeholders identified needs and barriers that were comparable to those from the family focus groups. Subsequent discussion summarizes responses by broad topic area.

Family Focus Groups

Family Needs

Families were asked to consider whether they thought that families of CYSHCN had different needs from families that did not have a CYSHCN. In general, families said that their needs were different. They mentioned that they needed more support and often lacked this. They noted that they have to be more careful about the environment their child is exposed to and that people often did not understand their need to be extra attentive to their child's health. They also commented on how much extra time is needed to care for their CYSHCN, how much more time they spent on medical needs, and about the extra needs for equipment, specialists, and child care centers. Families of CYSHCN felt that overall they had more stress in their lives. Some comments included:

“I have to be extra diligent with germs”
“You need more support”
“You need extra hands”
“People don’t understand”
“They need so much, doctors and all”
“You have something weekly or monthly”
“Couples suffer; they can’t get out as much”

Primary Resources

Families were asked about the primary resource person that they can turn to for assistance. Participants said that they turn to their families, but mainly have to rely upon themselves. They also mentioned the internet and several local agencies and providers including UCP, CRS Care Coordinators, CRS Parent Consultants, early intervention therapists, and primary care doctors. Some comments included:

“My mother is my hugest support.”
“Even though your family is great, they are not you.”
“Me and my laptop”
“You have to be the constant advocate.”
“Helps to talk with another parent (who has a child with special needs)”

Community Supports and Barriers

Families mentioned their own families and their churches as main sources of support in the community. They mentioned that many barriers created challenges and prevented families of CYSHCN from connecting to supports, especially transportation, financial issues, and lack of services. They also mentioned simply knowing about and finding services was a barrier, as was getting funding for services. Some comments included:

“Transportation”
“Lack of child care” (for other children in the family)
“Lack of knowledge regarding what services are available”
“No group meeting because we can’t have our kids in the same room.”
“Church”
“No time to do the research”
“Finding the services”
“There is nothing in the rural areas.”

Medical/Health Services

Families stated that they used primary care physicians in their local communities and CRS services, but for “everything else” they went to larger cities or out of state in some cases. (Many medical specialty services in Alabama are centered around cities with larger population density and surrounding the specialty children’s hospitals in Mobile and Birmingham.) Some comments included:

“I go to Birmingham for everything except for my primary care provider.”
“None in _____. You go to Birmingham or Nashville.”
“We go to Mobile for a specialist.”

Medical/Health Services Barriers and Strengths

When asked about barriers or issues they had encountered in obtaining needed medical services, results were somewhat different across the focus group sites and based on where the participant lived. Those from more rural areas said overwhelmingly that the lack of services within the community was the biggest issue. In terms of strengths, families mentioned several local agencies and that “knowing what you are legally entitled to” was the greatest strength. Some comments included:

- “No specialist in the area”
- “Keeping your income low enough to get financial support”
- “I just need more information.”
- “Taking off work”
- “The financial burden”
- “Coordinating the services”
- “Lack of knowledge about what services are available”

Dental Services

Families were specifically asked about access to dental services in the community. Families statewide said that only basic, if any, dental services were available locally and that they had to go to larger cities for most services. Some comments included:

- “They have to put him asleep, and no anesthesiologist would take him here.”
- “Dental care is a big issue.”
- “Nearest place for dental surgery is Birmingham.”

Education Services

Some reported success with inclusion of their CYSHCN in classrooms. Others discussed that they had tried to integrate their CYSHCN in the local schools, but there had been many challenges. They also commented that the educational system did not meet their particular needs.

Education Services Barriers and Strengths

Families mentioned the Alabama Disabilities Advocacy Program as a strength for its help in obtaining needed educational services. They mentioned the lack of specialty training in working with specific disabilities, especially autism, as a barrier. Some mentioned a general lack of support from the education system as a main barrier. Some comments included:

- “ADAP is a strength.”
- “Teachers need special training for children with special needs.”
- “More aids are needed.”
- “We have some good teachers, but few.”

Recreation Services

Families were asked about the availability of recreational opportunities in their communities. Depending upon the focus group site and where the participant lived, some opportunities were mentioned. Where opportunities were available, these tended to be parks, special camps, Upward Basketball, baseball, and Special Olympics. Families in the more rural areas felt that their CYSHCN did not have equal opportunities to meet and play with other children of similar ages. They cited a lack of basic amenities as a barrier.

Transportation

Transportation was discussed in terms of travel to appointments and to school. Some families said that transportation to school was provided, but that it was not fully accessible. Others mentioned that they had to travel the farthest for dental services and specialty care. Kid One Transport was mentioned as a strength and resource for transportation, but some participants noted there are limitations and difficulties with schedules.

Other Services

Families were asked to consider broadly any additional community services that would benefit CYSHCN and their families. Families mentioned respite care, support for siblings of CYSHCN, and support for caregivers. They also mentioned services to help with transition to adulthood, especially related to jobs after graduation from high school. Some comments included:

“Somewhere they (the sibling) can complain.”

“Just a break”

“The stress is everyday, seven days a week and there are not enough support groups for moms.”

“Not enough respite care, guidelines pretty strict”

Financial Issues

General discussion of financial issues included health insurance and financial burden. Families said that health insurance was a major financial concern, especially after age 21 years. They discussed insurance as not always affordable and not always covering the services needed by CYSHCN, especially equipment. They also mentioned restrictions placed on income in order to qualify for governmental supports. Additional costs for these families were related to missed work due to the child’s condition or hospitalizations. Some comments included:

“You have to be dirt poor; the system keeps you there.”

“If I’m out there working and make money, then I lose the money.”

Perhaps the most striking comment of all and the one that best captures the sentiments of the family focus groups was:

“We want a plan. We want to be part of the plan.”

Hispanic Focus Group

The issues that came from discussions during this focus group were similar to those presented above; however, some unique situations and challenges were apparent. Language/cultural and education/literacy issues clearly presented barriers for these families. These included not only the lack of bilingual staff at provider offices and agencies for CYSHCN, but also in learning the language in general. There was an overarching expression of the need for bilingual staff in the medical, educational, and support community. The group felt that language issues combined with lower educational/literacy levels limit the ability of the Latino population to use information technology, navigate health systems, and learn about resources for their CYSHCN. Also, acculturation could be even more difficult for Latino families with CYSHCN, leaving them somewhat isolated from society. This was partially due to fear and mistrust within the community, but also from a lack of linkages with services in general or from services that have a monocultural focus. Financial issues – especially time away from work and low wages in the community – and the lack of health insurance or adequate health insurance were of concern for these families. These

Latino families relied heavily on faith-based organizations for support. In addition to the above, barriers were similar to those discussed in the English-speaking focus groups.

Youth Focus Group

Youth Needs

When asked if they thought that their needs were different from the needs of youth without special health care needs, the youth participants said that they felt they did have different needs, but overall had more similarities. Some comments included:

“I don’t really think so; only my ability to walk is affected.”

“Yes and no; I have problems walking, but my mind and my spirit is just the same.”

Primary Resources

Most youth said that they usually go to a friend or family member when they have a need or a question, but they also said that sometimes they don’t go to anyone. Some comments included:

“My mom”

“My brother”

“I go to my sister.”

“Friends. I would not go to family first.”

“I just go into my room and hide if I don’t have someone else to talk to.”

“I usually just hold my emotions in. I don’t really talk about it.”

“I don’t really have anyone to talk to.”

Medical Services/Community Supports

Youth commented very little on direct medical services, but referred more to supportive services. They mentioned school and family resources as community supports.

Community Access

The youth said that finances and physical limitations present the biggest challenges to them accessing places in the community that other kids can.

Educational Services

Youth discussed the services they receive in school, mainly therapies, personal aides, and access to the school counselor. They were not as aware of being involved in the planning processes of their school services.

Recreational Activities

When asked what they do in their free time, the youth said they do a wide variety of activities. These included sports, computer activities, reading, drawing, playing piano, singing, church activities, going to the park, and talking with friends.

Health Behaviors

When asked if anyone talks with them about smoking, diet, sexuality, and alcohol, youth participants said they knew what those were but no one had talked to them specifically about these subjects.

Transition and Independence

Youth participants said that having a car was important to gaining independence in general. Other aspects of transition were discussed.

Medical Independence

When asked if they got to talk with their doctor without a parent present, the youth said that usually a parent or grandparent was in the room during their doctor's visits. Some comments included:

“Usually my dad is there, and that is really important for him.”

“My mother is a ‘mother hen.’ She feels that it is her job.”

Insurance Independence

When asked if they were aware of insurance and how much their family pays for their care, youth said that they knew about insurance but did not comment on the costs. Most were aware of the basic idea of a health insurance plan but little beyond that.

Future Jobs/Work

Youth were asked if they were concerned about finding a job or a worthwhile activity during the day in the future. Participants said that they had some concerns about finding a job, but overall felt that they would be able to accomplish that goal. Some comments included:

“Yes. My ability to not be able to walk makes me think that I am not going to be able to do a whole lot of stuff.”

“I think that I will be able to work.”

“I worry that I won't be able to find a job that I like and that I'm good at.”

“I think that I am determined; that it is going to be when I get a job, not if.”

Transition Planning

When asked about transitioning into adulthood, the youth did not know of a transition plan but knew they would want to be independent from their parents when they became adults. For example, one youth participant said,

“I don't want to live in my mom's basement until I am 47.”

The final part of the discussion centered on youth self-perception. When asked if they consider themselves to have a disability, the youth said they feel “normal” and that defining “normal” is subjective. Perhaps the most striking comments and those that best capture the sentiments of the youth focus groups came from this discussion. For example:

“I don't think that I am incapable of doing anything!”

“We are what we think we are.”

“... people might say that we are not normal, and we are normal! This is our normal.”

Key State Stakeholders Focus Group

In general, this group expressed similar views to those discussed by families in the family focus groups. They perceived families with CYSHCN as having needs that are generally more intensified than for families without CYSHCN, particularly in regard to financial concerns, family relationships, and strains on time and human resources. In addition to echoing the barriers as discussed in the family groups, most talked about lack of knowledge and trust issues as huge barriers in accessing

services. They mentioned that occasionally relationships between parents and providers can become strained during the process of identifying needs and determining what services will be provided. They felt that parents are oftentimes reluctant to share what is going on in the home and may experience feelings of denial or fear of being seen as “doing a bad job of parenting.” All agreed that there should be more education for the general public about disability, especially those conditions that are not as obvious physically. There was general agreement that it is difficult for services to meet needs statewide due to geographic location, travel requirements, and the need for families to take time off work. Participants felt that transition services were greatly lacking in the state, mainly because they are unavailable in rural areas and tended to drop off into adulthood. Though they did note that some recreational opportunities exist for CYSHCN, these participants said that community parks and playgrounds need to be more accessible. Most agree that there is no good transportation infrastructure for anyone, perhaps due to unrealistic federal regulations, liability insurance, funding, ignorance, and long waiting periods. Finally, the group discussed system strengths as Kid One Transport, Alabama Medicaid’s Patient First Program, Children’s Health System, Medicaid travel vouchers, media attention, and the combined insurance application for All Kids, Medicaid, and the Child Care Foundation.

OVERALL VIEW OF SECONDARY AND PRIMARY DATA CONCERNING CYSHCN AND THEIR FAMILIES

Secondary data and primary data from providers, families of CYSHCN, and youth with SHCN were remarkably similar regarding the priority health problems, service gaps, and status of the present service system. Although the rank order is different, providers and families identified similar top barriers to CYSHCN receiving services. Also, focus group themes supported these findings. Tables 37 and 38 below display these results.

Table 37. Statewide barriers to obtaining services for CYSHCN and families; provider and family responses, 2009

| Rank | County-Level Provider Survey | Family Survey |
|-------------|--|------------------------------------|
| 1 | Transportation | Insurance didn’t cover services |
| 2 | Families unsure how to use the system | Didn’t know where to go/who to see |
| 3 | Lack of child care | Missed school days |
| 4 | Lack of information on resources and health needs | Transportation |
| 5 | Insurance does not adequately cover needed health and related services | Can’t afford co-pays/deductibles |

Table 38. Common focus group themes and concerns, families, 2009

| |
|--|
| Lack of services |
| Not knowing where to go or who to see |
| Affordability/adequacy of insurance (co-pays, deductibles) |
| Transportation |
| Work conflicts |
| Needing to stay below a certain income level for government services |

As displayed above, transportation was mentioned in all three primary data sources. Also, “families unsure how to use the system” and “lack of information on resources and health needs” from the

county-level provider survey is equivalent to “didn’t know where to go/who to see” on the family survey and “not knowing where to go or who to see” from the focus groups. In addition, “insurance does not adequately cover needed health and related services” from the county-level provider survey is comparable to “insurance didn’t cover services” and “can’t afford co-pays/deductibles” from the family survey as well as the theme of “affordability/adequacy of insurance” in the focus groups.

In terms of service needs, again there were similarities between the primary data sources. Although key informants mentioned more health services when asked about the greatest needs in their counties, they did identify “most difficult” services to obtain that were similar to services that families reported they needed but had been unable to obtain. Most of these were community-based services (all were for families and all but one was for key informants). Transition services were mentioned by key informants, families, and youth. Table 39 below summarizes these results.

Table 39. Service needs and concerns compared; providers, families, and key informants, 2009

| Top 5 needs not obtained – family survey | Top 5 most difficult services to obtain - key informant interviews | Top 5 greatest needs – key informant interviews |
|---|---|--|
| Summer/after-school care | Respite | Transportation |
| Recreation opportunities | Transportation | Respite |
| Planning for transition | Recreation opportunities | Therapies (PT, OT, SP, nutrition) |
| Family supports | Planning for transition | Specialty care |
| Child care facilities/day care | Mental health/behavioral services <i>and</i> Summer/after-school care | Child care <i>and</i> Mental health/behavioral |

Availability of Care

Across all focus groups, families and state stakeholders discussed availability of care as a significant issue in obtaining necessary services for their CYSHCN. Families discussed the limitations of care in local communities, especially for specialty care and dental services. On family surveys, 16.8 percent of respondents indicated “providers not available” as a key barrier they had experienced. Many services were rated by key informants as “harder than you would expect” in terms of burden on families to obtain them. The lack of providers and the lack of facilities with convenient hours/locations were among the top five barriers in the county-level provider survey for both rural regions and Black Belt counties. In addition, families, state stakeholders, key informants, and county-level providers discussed transportation issues related to the increased travel required to access specialty services, typically located in more urban settings.

Availability of care either within a county or in an adjoining or neighboring county was addressed through the county-level provider survey. For most health and community-based services, care was available in either of these methods. Statewide, only respite care, summer/after-school care, and transportation assistance were available (in the county or in a neighboring county) in less than 90 percent of counties. Geographic and Black Belt differences were noted, with additional difficulties noted for hearing services, equipment/braces, family supports, planning for transition, and recreational opportunities. As discussed previously, however, availability tells only half the story. Key informants rated 12 of 23 services as “harder than you would expect” for families to obtain statewide. The most difficult services to obtain were identified as respite care, transportation

assistance, recreational opportunities, planning for transition, mental health/behavioral, and summer/after-school care. Of services identified by families as needed during the previous year, 20 percent or more were unable to obtain the following services: child care, family support, planning for transition, recreational opportunities, respite care, summer/after-school care, and transportation assistance. All of these are community-based services. Community-based services were the services most commonly reported as difficult to obtain across all groups. The most difficult to obtain health services reported by families were for mental health/behavioral, occupational therapy, speech therapy, and nutrition. Key informants rated pediatric therapies (as above) and respite as two of the three greatest needs statewide.

There was a slight trend for key informants to identify more gaps in health services; however, all groups recognized the limitations of availability for community-based services and supports to families. There were also differences in terms of barrier identification between families and providers. Even with these delineations, there was remarkable similarity of responses across the groups in terms of service availability, unmet need, and difficulty to obtain service data. These findings are all based on perceptions and individual experiences. Any discrepancies may indicate true differences, but may also, to some degree, indicate a need to provide ongoing provider education related not only to the unique needs of CYSHCN but also to specific standards for comprehensive care provision for CYSHCN. This also illustrates the importance of family and youth partnerships in their care and participation in policy-making efforts.

Both the scarcity of resources in general and the disparity of these services between urban and rural settings increases difficulties for families through costs for transportation and time away from home and work for extensive travel. It also creates complex service systems in the State. Although many of the services critical to the health and well-being of CYSHCN are centrally located in urban areas, CRS operates 15 community-based offices throughout the state to increase access to care for CYSHCN and their families. Through CRS staff, arrangements with local vendors, and service agreements with community providers and hospitals, CRS provides health care and related services to CYSHCN in every county within the state.

In summary, the most significant priority health needs and service gaps were in the following areas:

- 1) inadequate access to culturally competent care coordination services for CYSHCN, including transition planning as appropriate;
- 2) inadequate family and youth support services to promote increased participation in CYSHCN policy-making; and
- 3) inadequate access to community-based services for CYSHCN and families (including respite care, recreational opportunities, transportation, child care, and school-based services).

SECTION 3 SELECTION OF PRIORITY NEEDS AND DEVELOPMENT OF STATE PERFORMANCE MEASURES

Development of Priority Needs

List of Potential Priorities

Children and Youth with Special Health Care Needs

The following list of potential priority needs for CYSHCN in Alabama was developed by the CRS smaller needs assessment leadership team based upon the findings from primary and secondary data sources.

Table 40. Potential priority needs for CYSHCN

| |
|---|
| 1. Increase family and youth awareness of specific disabilities/conditions |
| 2. Improve the cultural competence of services available to CYSHCN and families |
| 3. Increase access to care coordination services for CYSHCN |
| 4. Increase awareness of medical home concept for providers and families |
| 5. Increase family knowledge of resources available to CYSHCN and families |
| 6. Improve the health status of CYSHCN through increased access to primary, specialty, and subspecialty care |
| 7. Increase family and youth participation in CYSHCN policy-making through support services and education/training |
| 8. Increase access to planning for transition to all aspects of adulthood (work, school, independence) for youth with special health care needs |
| 9. Increase availability of comprehensive health insurance coverage to CYSHCN through advocacy and educational efforts targeted at public and private insurance programs and outreach to families |
| 10. Promote increased access to community-based support services for CYSHCN and families, including respite care and recreational opportunities through education, awareness, advocacy, and linking families with resources |

1. Increase family and youth awareness of specific disabilities/conditions

This potential need was included for consideration based on results from the family and youth surveys, specifically the informational needs section. This was one of the top requests for both groups. It also ranked in the top five in importance among several of the small groups at the final CRS Needs Assessment Advisory Committee meeting and was subsequently ranked high in terms of feasibility. Several groups suggested it could be combined with other potential needs. CRS ultimately chose to include this need as a part of two broader needs to allow more flexibility and further reach of activities rather than to include it as a stand-alone need.

2. Improve the cultural competence of services available to CYSHCN and families

This potential need was included for consideration based on results from the family survey, specifically the differences noted between the groups who answered the survey in English compared with those who answered in Spanish. Also, the focus group held in Spanish supported its inclusion. It did not rank in the top five for importance among any of the small groups from the final CRS Needs Assessment Advisory Committee meeting. CRS ultimately chose to include this need as a part of a broader need to allow a comprehensive approach to service delivery and to build upon current activities.

3. Increase access to care coordination services for CYSHCN

This potential need was included for consideration based on results from the county-level provider, family, and youth surveys as well as all focus groups and data from the National Survey of Children with Special Health Care Needs. Results indicate a theme from both families and providers that CYSHCN and their families often don't know where to go or who to see for services or have difficulty navigating the system of care. Also, CRS has increased its capacity in this area over the past two years by adding a Care Coordination Specialist in the State Office, solely focused on strengthening care coordination services within the program. This need ranked in the top five for importance among several of the small groups at the final CRS Needs Assessment Advisory Committee meeting and was subsequently ranked high in terms of feasibility. Several groups suggested that this need become a foundation and vehicle for activities related to several other potential needs. Advisory Committee members recommended broadening this need to encompass activities related to other potential priority needs. CRS ultimately chose to select this as a priority need with the recommended expansion. This need encompasses cultural competence, transition planning (via specially-trained care coordinators focused on transition), and increasing family knowledge of resources available and awareness of specific disabilities and conditions.

4. Increase awareness of medical home concept for providers and families

This potential need was included for consideration based on results from the family and youth surveys and data from the National Survey of Children with Special Health Care Needs. It ranked in the top five for importance for one of the small groups at the final CRS Needs Assessment Advisory Committee meeting and was subsequently ranked high in terms of feasibility. CRS ultimately did not select this as one of its priority needs for further planning since these efforts are addressed in activities toward National Performance Measure #3, through Healthy People 2010 initiatives, and through other partner projects, including training through Alabama Medicaid.

5. Increase family knowledge of resources available to CYSHCN and families

This potential need was included for consideration based on results from the county-level provider and family surveys, as well as the family focus groups. It also ranked in the top five for importance among several of the small groups at the final CRS Needs Assessment Advisory Committee meeting and was subsequently ranked high in terms of feasibility. Several groups suggested it could be combined with other potential needs. CRS ultimately chose to include this need as a part of two broader needs to allow more flexibility and further reach of activities rather than to include it as a stand-alone need.

6. Improve the health status of CYSHCN through increased access to primary, specialty, and subspecialty care

This potential need was included for consideration based on results from the county-level provider survey and key informant interviews. Also, there was support for its inclusion in the family surveys and family focus groups. This is a current priority need for Alabama's CYSHCN. It ranked in the top five for importance among several of the small groups at the final CRS Needs Assessment Advisory Committee meeting, but was subsequently ranked low in terms of feasibility. CRS ultimately did not select this as one of its priority needs for further planning since the family survey results pointed to greater issues with community-based services and other issues seemed to warrant focus. Also, the CRS program will continue its ongoing efforts towards increasing access to health and related services through its system of 15 community-based offices statewide and through partnerships with other members of the system of care for CYSHCN in the State.

7. Increase family and youth participation in CYSHCN policy-making through support services and education/training

This potential need was included for consideration based on results from the family and youth surveys and focus groups. The education and training component was also supported through the county-level provider survey and key informant interviews. It is similar to a current priority need for Alabama's CYSHCN. It did not rank in the top five for importance among any of the small groups from the final CRS Needs Assessment Advisory Committee meeting. However, CRS ultimately chose to select this as a priority need. This choice is based not only on the data itself, but also due to internal capacity to impact change through State and Local Parent Consultants and Advisory Committees and on opportunities to partner with support and educational organizations. These include the Alabama Parent Education Center and Family Voices of Alabama, which is also a newly funded Family to Family Health Information Center. This need encompasses not only direct supports for participation, but also increasing family knowledge of resources available, awareness of specific disabilities and conditions, and other educational/training opportunities.

8. Increase access to planning for transition to all aspects of adulthood (work, school, independence) for youth with special health care needs

This potential need was included for consideration based on results from the family and youth surveys and focus groups as well as the key State stakeholders focus group, county-level provider surveys, key informant interviews, and data from the National Survey of Children with Special Health Care Needs. It ranked in the top five for importance for several of the small groups at the final CRS Needs Assessment Advisory Committee meeting, but was subsequently ranked lower in terms of feasibility for most groups. CRS ultimately did not select this as one of its priority needs for further planning since these efforts are addressed in activities toward National Performance Measure #6 and through Health People 2010 initiatives. Also, this need will be addressed through a broader effort and new priority need related to care coordination. This included specially trained care coordinators who work solely with youth of transition age.

9. Increase availability of comprehensive health insurance coverage to CYSHCN through advocacy and educational efforts targeted at public and private insurance programs and outreach to families

This potential need was included for consideration based on results from the family, youth, and county-provider surveys, and family and key State stakeholders focus groups. It ranked in the top five for importance for several of the small groups at the final CRS Needs Assessment Advisory Committee meeting, but subsequently ranked low in terms of feasibility. CRS ultimately did not select this as one of its priority needs for further planning since these efforts are addressed in activities toward National Performance Measure #4 and Healthy People 2010 initiatives. CRS has ongoing partnerships with ALL Kids (Alabama's SCHIP) and Medicaid to address system issues that impact CYSHCN and their families. Also, local CRS office staff work with families to assist them in applying for all third-party resources for which they may be eligible and to assure that they understand and make the best use of their benefit packages.

10. Promote increased access to community-based support services for CYSHCN and families, including respite care and recreational opportunities through education, awareness, advocacy, and linking families with resources

This potential need was included for consideration based on results from the family and county-provider surveys and family and key State stakeholder focus groups. It also ranked in the top five for importance among several of the small groups at the final CRS Needs Assessment Advisory

Committee meeting and was subsequently ranked in the mid to high ranges in terms of feasibility. Several groups suggested that this need could be expanded to include additional services that stood out as difficult to obtain from the surveys. They also noted that this would be another avenue for family support and training in advocacy and awareness. It is also related to care coordination. CRS ultimately chose to select this as a priority need with recommended expansions to include transportation assistance, child care, and school-based services.

Methodologies for Ranking/Selecting Priorities

Through the FY 2009-10 MCH needs assessment process, Family Health Services and CRS respectively identified seven and three MCH priority needs, with each agency identifying their needs through their components of the needs assessment.

Children's Rehabilitation Service

The final CRS Needs Assessment Advisory Committee meeting occurred in December 2009, focusing on a presentation of the analyzed data and a discussion of priority needs for CYSHCN. Attendants were randomly divided into one of five small groups to consider the list of suggested priority needs. They were allowed to add or alter based on their interpretation of the information presented. No new needs were added, but attendants did suggest some combinations of needs, as mentioned above. Small group facilitators led discussions about the information and instructed members to select which potential needs they believed were the top five priority needs for CYSHCN in Alabama. A second process was then facilitated such that members then ranked those top five priority needs according to their assessment of the feasibility of addressing that need (i.e. how likely it was that the State CSHCN program and the State system of care for CYSHCN could implement activities to address the proposed need). Results were tallied for each group and then a report was generated for use in the final consideration of priority needs.

CRS State Office administrative staff, including the State Parent Consultant, and all eight district supervisors (CRS Administrative Team) participated in a follow-up meeting to review the input of the committee and their thoughts on the needs assessment data. The group discussed the importance and feasibility rankings of the potential priority needs from the advisory committee, current CSHCN program activities, and the National and State performance measures for CYSHCN. The group also gave careful consideration to the financial and human resources available, what was already being done around these needs (within and outside the CSHCN program), and focused on existing gaps where CRS has the mission and the capacity to address the need. Based on these considerations, the group identified three priority needs for further development and planning. Two of these three identified priority needs were re-worded from those presented to the advisory committee to be more inclusive and allow activities that more broadly address several separate potential needs. The third need was selected as it was originally written. These three priority needs were then entered into the MCH Capacity Assessment Grid and rated by the CRS State Office administrative staff at a separate meeting.

Three state-negotiated performance measures were drafted, including appropriate measurement strategies. The priority needs and draft measures were then electronically sent back to the CRS Administrative Team for final comment and approval.

Priority Needs and Capacity

Children and Youth with Special Health Care Needs

Enabling Services

Priority Need #1: Increase access to culturally competent care coordination services for CYSHCN, including transition planning as appropriate.

This priority need is new for the 2009-2010 needs assessment cycle. Current needs assessment findings from the county-level provider and family surveys as well as focus groups indicate that families of CYSHCN often don't know where to go or who to see for services or have difficulty navigating the system of care and may need assistance in connecting with resources at the local level. Youth and family surveys also highlight the importance of culturally competent care coordination and its impact on transition planning. Support for the selection of this need also includes data from the National Survey of Children with Special Health Care Needs, which indicated that almost 40 percent of Alabama CYSHCN did not receive all elements of needed care coordination. Planning for this need will require special consideration to cultural-language barriers/cultural competence and geographic differences. Based on ratings of areas covered in the MCH Capacity Assessment Grid, this priority earned 52 of 60 possible total points and ranks number one of three priority needs for CYSHCN.

Infrastructure-Building Services

Priority Need #2: Increase family and youth participation in CYSHCN policy-making through support services and education/training.

This priority need is similar to one identified in the previous needs assessment cycle, with more focus on supports, education, and training. This need encompasses direct family and youth supports as well as enabling supports for participation in program decisions and policy development. It calls for planning and implementation of activities across all aspects of the service system for CYSHCN in the state and relies heavily on both direct supports and on education and training via existing family and youth networks and through new partnerships. Through the surveys and focus groups, families of CYSHCN and youth with SHCN reported a variety of needs for support services, informational materials, and training. According to the county-level provider surveys, family supports are less available, especially in the Rural South. Key informant interviews show that they are harder than would be expected to obtain statewide, and especially in rural areas and Black Belt counties. Planning for this need will require special consideration for cultural-language barriers and geographic differences. Based on ratings of areas covered in the MCH Capacity Assessment Grid, this priority earned 50 of 60 possible total points and ranks number two of three priority needs for CYSHCN.

Priority Need #3: Promote access to community-based services for CYSHCN and families (including respite care, recreational opportunities, transportation, child care, and school-based services) through education, awareness, advocacy, and linking families with local resources.

This priority need is new for the 2009-2010 needs assessment cycle. Current needs assessment findings from the county-level provider and family surveys as well as family and key State stakeholder focus groups indicate that families of CYSHCN have great difficulty accessing community-based services – often more difficulty than experienced for health and related services.

All of those listed above were ranked by key informants as “harder than you would expect” for families to obtain, statewide and by geographic or Black Belt designations, and were ranked as some of the greatest needs for local areas. They were also less available according to the county-level provider surveys. Family survey data also supports the selection of this need. Of all 23 services listed, only seven were reported as needed but not obtained by greater than 20 percent of respondents. All seven of these services were community-based services, including those targeted by this priority need. Activities toward meeting this need will rely heavily on education and awareness for youth, families, and providers related to what services are available and what are needed at the local levels. It will require data dissemination from the needs assessment, support for and stimulation of grassroots efforts to develop local delivery systems, and advocacy and leadership training for families and youth – empowering them as agents of change in their local communities. Planning for this need will require special consideration for cultural-language barriers and geographic differences. Based on ratings of areas covered in the MCH Capacity Assessment Grid, this priority earned 36 of 60 possible total points and ranks number three of three priority needs for CYSHCN.

Priority Needs and State Performance Measures

Children and Youth with Special Health Care Needs

State Performance Measures have been developed for all three priority needs identified for CYSHCN and their families. A checklist measurement tool has been created for each new performance measure.

➤ State Performance Measure #1: Provide increased access to care coordination services for CYSHCN

This performance measure is linked to priority need #1 (increase access to culturally competent care coordination services for CYSHCN, including transition planning as appropriate). A checklist measurement tool of five characteristics that promote increased access to care coordination services will be used to measure progress toward this new objective. Each characteristic will be measured on a 0 – 3 scale (not met, partially met, mostly met, and completely met), bringing the total possible scores for progress toward the entire measure to 15. Objective criteria have been set for each score. The characteristics are:

- The State CSHCN Program **develops materials, modifies existing materials, and/or disseminates public awareness materials** regarding the Care Coordination Program and other related issues (condition/disability-specific, cultural competence, family-centered care, medical home, transition, care coordination) to increase awareness and knowledge of resources available to CYSHCN and their families.
- The State CSHCN Program **establishes and maintains a Care Coordination Taskforce** (including representatives from local staff and parent consultants) to provide leadership and **maintains an updated Care Coordination Manual** to guide implementation of the program statewide.

- The State CSHCN Program hosts or provides **ongoing care coordination training** for staff at state and local levels.
 - The CSHCN Program staff, including parent consultants, **maintain a working knowledge of local resources to assist in linking and referring CYSHCN and their families** to services as needed. Host or directly **provide trainings and/or resource fairs** for CYSHCN and their families in local communities to increase awareness and knowledge of care coordination services and other available resources.
 - Each child or youth enrolled in the State CSHCN program is **assigned to a local care coordinator** (traumatic brain injury or transition care coordinator as appropriate and available) and **has an active comprehensive plan of care** in place that addresses identified needs, integration into local communities, independence, and transition planning.
- State Performance Measure #2: Promote increased family and youth participation in CYSHCN policy-making
- This performance measure is linked to priority need #2 (increase family and youth participation in CYSHCN policy-making through support services and education/training). A checklist measurement tool of five characteristics that promote increased family and youth participation in CYSHCN policy-making will be used to measure progress toward this new objective. Each characteristic will be measured on a 0 – 3 scale (not met, partially met, mostly met, and completely met), bringing the total possible scores for progress toward the entire measure to 15. Objective criteria have been set for each score. The characteristics are:
- The State CSHCN program, in collaboration with Alabama’s Family to Family Health Information Center, **supports families of CYSHCN and youth with special health care needs to participate in state and local taskforces/committees**, inter-agency meetings, and partner agency initiatives to represent the unique needs of CYSHCN and to promote a comprehensive, collaborative effort to increase their participation in policy-making.
 - The State CSHCN program collaborates with Alabama’s Family to Family Health Information Center to **promote leadership development initiatives** for families of CYSHCN and youth with special health care needs.
 - The State CSHCN program staff, including Parent Consultants, in partnership with appropriate advocacy agencies and service providers, host or directly **provide training for families of CYSHCN and youth with special health care needs** including condition/disability-specific issues, special education rights, local resources, etc. to support increased knowledge and effective participation in policy-making.
 - The State CSHCN program, in collaboration with partner agencies, **develops new materials, modifies existing materials, and/or disseminates resources** related to the unique needs of CYSHCN, including condition/disability-specific information and the core components of cultural competence, family-centered care, and care coordination to support increased knowledge and effective participation in policy-making.

- The State CSHCN program **maintains active parent and youth advisory committees** (state and local), **employs parent and youth consultants**, and **strengthens parent-to-parent networks** to support increased knowledge and to promote effective participation in policy-making by families of CYSHCN and youth with special health care needs.

➤ State Performance Measure #3: Promote access to community-based services for CYSHCN and families

This performance measure is linked to priority need #3 (promote access to community-based services for CYSHCN and families [including respite care, recreational opportunities, transportation, child care, and school-based services] through education, awareness, advocacy, and linking families with local resources.) A checklist measurement tool of five characteristics that promote access to community-based services will be used to measure progress toward this new objective. Each characteristic will be measured on a 0 – 3 scale (not met, partially met, mostly met, and completely met), bringing the total possible scores for progress toward the entire measure to 15. Objective criteria have been set for each score. The characteristics are:

- The State CSHCN program staff, including Parent Consultants, **participate in state and local taskforces/committees**, inter-agency meetings, partner agency initiatives, and local community efforts to represent the unique needs of CYSHCN and to advocate for increased access to community-based services (transportation, recreational opportunities, respite care, child care, school-based services, etc.).
- The State CSHCN program staff, including Parent Consultants, host or directly **provide training and technical assistance for community-based organizations** to increase awareness of the unique needs of CYSHCN and their families and to promote access to necessary services in local communities.
- The State CSHCN program staff, including Parent Consultants, host or directly **provide training for families of CYSHCN and youth with special health care needs** to increase knowledge of services that may benefit them, to increase awareness of local community resources, and to support and promote effective advocacy for needed community-based services.
- The State CSHCN program staff, including Parent Consultants, maintain a **working knowledge of local community-based resources and assist in linking or referring CYSHCN and their families** to services as needed. They also monitor service needs that are unable to be met in local communities and share these with appropriate policy-makers.
- The State CSHCN program **analyzes the 2009-2010 MCH Needs Assessment findings to develop community-level reports and disseminates these to local policy-makers** to help identify strengths and gaps/needs for community-based services in the local area.

Final Comments

Progress related to the three performance measures described above will be measured in an ongoing fashion and will be reported to the federal government annually through the Maternal and Child Health Services Block Grant Report/Application for funds. Through its role as the State CSHCN Program, CRS will develop activities that promote efforts to address these identified needs. The information and data gathered during this needs assessment will assist CRS in program planning and will also be made available to community stakeholders to support grassroots efforts to meet local needs. Since needs assessment is a continuing process, CRS will monitor the impact of activities and collaborate with partners and stakeholders to proactively address emerging needs. Through ongoing needs assessment, program planning, collaboration, advocacy, and public awareness, CRS will continue to promote and strengthen Alabama's system of care for children and youth with special health care needs and their families.