VOICES of Alabama’s Children and Youth with Special Health Care Needs and Their Families

A part of the

Children and Youth with Special Health Care Needs portion of Alabama’s 2009/10 Maternal and Child Health Needs Assessment

FAMILY VOICES of Alabama

CHILDREN’S Rehabilitation Service

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
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ACKNOWLEDGMENTS

Conducting this needs assessment required that individuals, groups, and organizations come together to develop a plan and collect information that would describe the strengths and challenges in the current system of care for children and youth with special health care needs (CYSHCN). This could not have happened without a successful collaborative effort involving a range of stakeholders; we extend a sincere word of gratitude to all who facilitated this process. Specifically, we acknowledge the CYSHCN and their families for their vital input, dedication, time, and collaboration. Thank you to community groups such as Family Voices of Alabama, the Alabama Parent Education Center, the Arc of Alabama, United Cerebral Palsy of Alabama and to the many clinics and healthcare providers who helped distribute the surveys. Thank you to the facilities used to conduct the focus groups including: the Bass Pro Shop of Prattville, the Clarke County Arc, the Huntsville Library, the Alabama Department of Rehabilitation Services (Montgomery), Prince of Peace Catholic Church in Hoover, and Tuscaloosa Church of Christ. Thank you to Cathy Cartagena from UAB Division of Preventive Medicine for her interpretation services. Thank you to the Needs Assessment Advisory Committee members for all their time and input. Lastly, a special thank you to Susan Colburn of Family Voices of Alabama for her help in coordinating the focus groups and developing the surveys.
INTRODUCTION

Title V

The Maternal and Child Health Services Title V Block Grant serves to improve the health and well being of women, children, and families across the United States. Part of Title V funding goes specifically to support children and youth with special health care needs (CYSHCN) and their families. Every five years, Title V programs in each state are required by federal law to conduct statewide needs assessments. The Title V program for CYSHCN in Alabama is housed in CRS, a division of the Alabama Department of Rehabilitation Services.

Partnerships

In summer 2009, as part of the statewide needs assessment for 2010, CRS sponsored and partnered with Family Voices of Alabama and the University of Alabama at Birmingham’s School of Public Health, Department of Health Care Organization and Policy (Maternal and Child Health concentration) to develop and implement surveys and conduct five focus groups across Alabama.
WHO RESPONDED?

Family Surveys: English Speaking
- 1,071 family members participated
- Approximately 83% had one child with special needs
- Average age of their CYSHCN was 11 years old
- Most reported their CYSHCN to have a moderate form of disability
- 63% had health insurance through Medicaid or Medicare
- Majority of family members who responded were Caucasian, married females
- Most had a high school education

Family Surveys: Spanish Speaking (Latino)
- 32 family members participated
- Majority had one child with special needs
- Average age of their CYSHCN was 9 years old
- Most reported their CYSHCN to have a moderate form of disability
- Most common form of health insurance was Medicaid or Medicare
- Majority of family members who responded were Hispanic, married females
- Most had less than a high school education

Youth Surveys: English and Spanish Speaking
- 331 English speaking youth and 5 Spanish speaking youth responded
- Almost equal numbers of males and females; 2/3 were white
- A majority (84%) lived with their parents or other relatives
- Educational levels were generally appropriate for their age
FOCUS GROUPS

<table>
<thead>
<tr>
<th>Location</th>
<th>Group</th>
<th>Date</th>
<th>Focus Age Range</th>
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<tr>
<td>Prattville</td>
<td>Youth</td>
<td>6/20</td>
<td>12-24 years</td>
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<tr>
<td>Jackson</td>
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<td>Huntsville</td>
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<td>8/6</td>
<td>&lt; 6 years</td>
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<tr>
<td>Birmingham</td>
<td>Hispanic</td>
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<td>n/a</td>
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<tr>
<td>Tuscaloosa</td>
<td>Family</td>
<td>9/14</td>
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Family

Family members attending: 26 mothers, 4 fathers, and 2 grandparents of CYSHCN; 24 had one CYSHCN, 16 had 2 CYSHCN, and 1 had 3 CYSHCN.

Participant Counties: 6 from Jefferson, 2 Shelby, 3 Clarke, 5 Washington, 5 Tuscaloosa, 2 Madison, 1 Choctaw, 1 Escambia, 1 Mobile, 1 Wilcox, 2 Conecuh.

Race/ethnicity: 16 Caucasian, 8 Latino/Hispanic, and 7 African American.

Educational levels: 7 less than high-school, 7 had high-school diploma/GED, 2 vocational training (after high-school), 5 with an associate degree, 4 some college, and 3 other.

Child age: ranged from 5 to 20 years with an average age of 10; the most commonly listed age of child was 17 years.

Primary health conditions/disabilities included: 6 with cerebral palsy, 3 autism, 2 Down syndrome, 2 ADHD, 2 spina bifida, 2 juvenile rheumatoid arthritis, 2 hearing impaired, 2 epilepsy, 2 cleft lip; others list a variety of conditions such as: learning disability, hearing impairment, ADD, mitochondrial melas, cystic fibrosis, brain damage, shaken baby syndrome, Crohn’s disease, seizures, eating disorders, encephalocele, hydrocephalus, microcephaly, and bilateral cleft palate.

Severity of condition: 17 moderate, 11 severe, and 5 minor.

Youth

Youth attending: similar number of males (4) and females (5)

Race/ethnicity: two-thirds self-identified as African American and one-third as Caucasian

Education levels: most were age-appropriate ranging from less than a high school education to some college

Primary health conditions included: 3 with seizures, 3 cerebral palsy, cleft lip, asthma, Asperger’s syndrome, ADHD, and shunt

Severity of condition: 5 reported their condition to be moderate and 4 as severe.
WHAT DID FAMILIES SAY?

Health & Health-Related Services

Figure 1

Non-Receipt of Needed Health Services for CYSHCN, Alabama 2009

Figure 1 represents the family members who said that their child needed a particular health service but did not receive that service. The next pages describe the top six reported health service needs. When available, personal statements or comments are included to highlight those issues.
Mental Health/Behavioral Services

More than one-quarter (27%) indicated that their children needed mental health/behavioral services; 16% of these reported they did not receive the services.

Selected Quotations:
“I was partially satisfied with mental health because they are constantly changing therapist and doctors.”

Occupational Therapy

More than 1 out of 3 said their child needed occupational therapy; approximately 15% of these reported not receiving these services.

Selected Quotations:
“They are not provided OT at all. If they can move there hands then that is enough. They don’t need OT.”
“My child did not receive early intervention for physical occupational therapy she needed.”
“Physical and occupational therapy dropped her at school this year.”

Speech Therapy

Four out of 10 families reported needing speech therapy for their child, but 13% of these did not receive this service.

Selected Quotations:
“My daughter is on the waiting list for speech therapy.”
“Speech in school not good.”
“Speech therapy is going to be started with this new school year.”

Nutrition Services

Approximately 27% needed nutrition services for their child. However, 12% of these families and caregivers reported that their child did not receive this service.

Selected Quotations:
“Child has diabetes and doesn’t see a nutritionist.”

Developmental Screening

One-third (35%) reported needing developmental screening for their child, but 10% did not receive this service.
Dental Services
Dental services were needed for more than half of the children, and about 9% did not receive this service.

Selected Quotations:
“Orthodontic care.”
“Dental care is a big issue.”
“The nearest place for dental surgery is Birmingham.”
“They have to put him asleep and no anesthesiologist would take him here.”
“For those of us with children that were not born in the U.S., there is a real problem with getting dental care.”
Community-Based Services

Figure 2

Non-Receipt of Needed Community Services for CYSHCN, Alabama 2009

Figure 2 represents those who said their child needed a particular community-based service but did not receive that service. The next pages describe the top six reported community-based service needs noted. When available, personal statements or comments are included to highlight those issues.
Summer/After-School Care
About 20% of families and caregivers reported needing summer/after-school care for their child; 42% who needed it did not receive this service.

Selected Quotations:
“Summer school was not offered at our school for special needs. After school care facility not available in our area.”
“My parents are looking at moving here to help. I’m a teacher; I need a place to put him.”

Recreation Opportunities
About 23% reported needing recreation opportunities for their child; one-third who needed it did not receive this service.

Selected Quotations:
“Recreation is needed for my child. We do not have it in the community or school.”
“Recreation and transportation services are very limited. There is a miracle league in existence for recreation however, my child prefers individualized sports like swimming, boating, biking, scooter, etc.”
“I wished there was a playground for children with special needs.”
“My child was denied physical education at school.”
“Camp Smile.”

Planning for Transition to Adulthood
About 14% of families and caregivers indicated that their child needed services for planning for transition to adulthood; of these, more than one-third did not receive this service.

Selected Quotations:
“Transition programs were to begin at age 16 – just now beginning to see some action now that he is about to graduate.”
“My son has real needs that are not addressed at the level he needs. His needs for transition into adulthood have not been addressed or given me any hope that Alabama has anything to offer.”
“I don’t want to live in my mom’s basement until I am 47.”
“I am working at a local fast food restaurant only part time while I am in college.”
“I am worried that I’ll not be able to keep a job; and I worry that I won’t be able to find a job that I like and that I am good at.”
**Family Support**
About 23% reported needing family support, but approximately one-third of these did not receive this service.

*Selected Quotations:*
“More support financially and socially with life coaches.”
“Family complains too much and sometimes get on my nerves but getting better.”
“The stress is every day, seven days a week and there is not enough support.”
“Groups for moms.”

**Child Care**
About 19% of families and caregivers reported needing child care for their child; almost one-third of these did not receive this service.

*Selected Quotations:*
“Because no one wanted the responsibility of caring for a child with a disability. He was a risk.”
“The centers that were available in my area refused to provide care for her due to some of her delays and her having a pacemaker. The only alternative I could find was extended school year, but she was not eligible for that.”

**Respite Care**
About 18% of families and caregivers reported needing respite care; one-quarter of these did not receive the needed service.

*Selected Quotations:*
“I think there should be more money in place to help with respite care.”
“Not enough respite care, guidelines pretty strict.”
Barriers to Accessing Services

Figure 3

Barriers to Receiving Services, Alabama 2009

Barriers are physical, legal, or other issues that limit or inhibit an individual’s or group’s ability to access services that are needed. Figure 3 depicts the barriers mentioned by families, from highest to lowest percent, who said that the issue was a barrier to receiving services. The next pages describe specific barriers noted by individuals who answered the family survey. Personal statements or comments are included to highlight those issues.
**Financial**

Nearly three-quarters of the families said that financial issues were a barrier including:

- Insurance didn’t cover services
- Can’t afford co-pays and deductibles
- Services too expensive
- No insurance

**Selected Quotations:**
“Services are steadily increasing but the costs are stressful for the family.”
“Medical expenses, co-pays, medical testing all too expensive, even with insurance!”
“Our insurance is quickly reaching max. Supplies and equipment too expensive to pay monthly rentals.”
“You can’t afford the insurance to cover the medical needs.”
“It’s a constant battle, insurance.”

**Work/School**

More than half listed work and/or school issues, such as:

- Missed school days
- Work conflict – unable to take time off work
- Work conflict – can’t afford to lose pay

**Selected Quotations:**
“Had to check him out of school a few times for services.”
“I quit work; he had too many problems at school.”
“I cannot work ‘9-5’ because of the 10 yr olds erratic schedule – have no insurance and been penalized for her school situation.”

**Provider or Service**

More than half of families and caregivers said that provider or service issues were barriers including:

- Waiting list for services too long
- Providers not available
- Hours/location of providers not convenient

**Selected Quotations:**
“End waiting list for programs.”
“This area is in great need of more services. I have to go to Birmingham which with my child it takes 4 hours to get there to go to the doctor. It takes all day just to see the doctor for about 15 or 20 minutes.”
“We just don’t have anything in _______ County.”
Care Coordination
About 25% listed care coordination issues, such as:

- Did not know where to go/who to see

Selected Quotations:
“I think that she has a significant problem but don’t know where to go.”
“I don’t know about all the options.”
“I was not satisfied with the fact that I could not FIND the services I needed for my daughter.”
“Lack of knowledge about what services are available.”
“No time to do the research.”

Transportation
About 21% listed transportation issues as a barrier.

Selected Quotations:
“Having a hard time paying for gas back and forth.”
“I think transportation should be more easy to get started.”
“Medicaid transport reimbursement took MONTH to be processed and sent.”

Child Care
- About 15% reported the lack of child care as being a barrier.

Selected Quotations:
“I am not able to work because I don’t know any daycare facilities who take children with special needs.”
“The biggest issue I have, other than the medical aspects of my child’s life, is childcare. Most centers are simply scared of the liability my daughter could be to their center. It is heartbreaking and exhausting. It also makes it hard to keep a steady job.”

Administration Issues
- About 9% of families and caregivers listed state policy or administrative barriers.

Selected Quotations:
“We make too much money to receive certain services.”
**Language/Cultural Issues**
- About 3% listed language/cultural issues as a barrier.

*Selected Quotations:*
“Language barriers are huge for finding out about events and participating.”
“Cultural barriers and we are ignorant about knowing how to treat children and youth with special health care needs.”
“Lack of information in Spanish.”

**Medical Home Availability**

**Primary Care Provider**
- 52% of families indicated having one or more people that they considered to be their child’s personal doctor or nurse.
- The child’s main health care providers almost always made family feel like a partner in their child’s health care.

**Care Coordination**
- More than half of families indicated having different doctors or services requiring care coordination.

**Developmental Screening**
- A majority of families indicated that their child had been regularly screened.
- Referrals as a result of the screening were almost always made.

**Interpreter Services**
- Most families from the English survey did not need an interpreter.
- Interpreter services were needed by a majority of families from the Spanish survey.
  - Most indicated they were sometimes or always able to get someone other than a family member to assist them with interpreting needs.
FAMILY AND YOUTH PERCEPTIONS

Transition Services
Figure 4 below presents some interesting contrasts between what the parents of youth with special health care needs (YSHCN) considered as priorities for their youth and what the youth reported as priorities as they indicated what was important in their future plans. It is important to note that the parents were asked if they had begun to make plans for any of the areas listed and the average age of their child was 11 years old. However, the youth were asked if their future plans included any of the issues listed and their average age was 18 years old. Given the slight difference in the way the questions were presented to the families and youth and the difference in average age, comparisons should be interpreted with caution.

Figure 4

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<th>Future Plans (%) Reported by Parents and YSCHN, Alabama 2009</th>
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<tr>
<td>Working for Pay</td>
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- Parent Response (%)
- Youth Response (%)
Health Information Topics

In addition to the differences seen between the youth's view of his or her future plans and the parents' views, there were also distinctions regarding health topics or issues that interested the parents and the youth.

- Families listed the following topics:
  - My child's condition or disability (42.8%),
  - Recreational activities (42%),
  - Successful persons living with condition/disability (36.9%),
  - Healthy behaviors (35.1%), and
  - Jobs/careers (31.3%).

- YSHCN ranked the following as their top five information issues:
  - Jobs/careers (50.9%),
  - My condition or disability (39.6%),
  - Further education and training (39.6%),
  - Healthy behaviors (31.5%), and
  - Successful persons living with my condition or disability (31.1%).

Health Care Independence

- Families indicated that their youth's doctors or health care providers often had not talked to the youth about adult health care needs
  - Greater than half of the youth said that their health care provider had not discussed adult health care needs with them

- Families also said that providers infrequently encouraged their youth to take responsibility for his or her health care needs
  - About 50% of the youth agreed that they had not been encouraged by health care providers to assume this responsibility
  - Most youth also reported that they had not had an opportunity to speak to their health care provider privately
What Did Youth Say?

Perceived Health Status
- 75.2% of youth reported their health status was “good”
- About 63% reported their health condition affected their ability “to do things”
- Felt they had different needs but overall had more similarities than differences with youth without special needs

Sources of Information & Support
- Parents and family members were commonly reported as sources of information for the youth
- Family members and schools were indicated as primary sources of support

Social Activities
- Majority spend time in social activities with people outside their homes
- Other frequently reported activities included:
  - Watching television
  - Listening to music
  - Time on the computer
  - Church activities
WHAT DID HISPANIC FAMILIES SAY?

For the Hispanic participant families the single most overarching barrier reported was isolation – both induced by issues interior to the Latino community (fear, mistrust, comfort in community, etc.) and through a lack of linkages with services oriented more towards a monocultural society. Specific issues mentioned included:

**Acculturation**
- Overriding issue throughout the focus group
- Families appear to be isolated to some extent from society
- Language/cultural barriers and lack of services

**Language**
- Language barriers was a consistent theme
- Primarily the lack of bilingual staff

**Education/Literacy**
- Low education and literacy to influence:
  - Ability to access resources
  - Ability to navigate health systems
  - Use of information technology
- Low awareness and knowledge about both CYSHCN conditions and service provision

**Financial**
- Most identified as being relatively low socio-economic status
- Low salaries and lack of adequate health care were noted barriers
- Losing work time to care for their children
- CYSHCN require more resources; created increasing financial needs

**Providers Serving the Latino Community**
- Shortage of bilingual providers and other staff trained to provide health and social services

**Services for Latino Community**
- Key needed health services were dental, vision, and qualified physical therapists
- All families who participated reported they did not have a set health care provider or continuity of care
COMMON THEMES

Reviewing common themes is a potentially useful method of strategizing priorities and creating a plan for intervention. Many barriers were expressed by the responding families and common themes among the Barriers to Accessing Services between the family focus groups and the family surveys were examined.

FOCUS GROUP COMMON THEMES

- Lack of Services
- Didn’t know 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

FAMILY SURVEYS COMMON THEMES

- Insurance didn’t cover services
- Didn’t know where to go or who to see
- Missed school days
- Transportation
- Affordability/adequacy of insurance (co-pays, deductibles)

COMMON THEMES FROM FAMILY SURVEYS and FOCUS GROUPS

- Didn’t know where to go or who to see
- Transportation
- Insurance
  - Affordability/adequacy of insurance (co-pays, deductibles)
**Services Needed But Not Received**
Barriers such as those listed above resulted in many families having an unmet need for health and community-based services. When families were asked about what services they needed and then if they received that service, clear gaps were revealed in need versus receipt of services. Some services were needed by the majority of families, such as primary care and, with the exception of the Hispanic families, most said they received this needed care. However, in other areas such as summer or after-school care, about 27% said they needed such care, but 42% of the families who said they needed such care did not receive it. Likewise, about one-third of the families who needed recreational opportunities, transitional planning, family support, or child care did not get what they needed. In general, community-based services showed higher percentages of non-receipt than did health and health-related services. Refer to Figures 1 and 2.

**STRENGTHS and CHALLENGES**

**STRENGTHS**
Though families and youth voiced that there were numerous challenges and opportunities for improvement in serving CYSHCN, they also pointed out several areas of support and strength such as community-based services and non-profit organizations that serve CYSHCN. In addition, many families had positive things to say regarding their experience with state-sponsored services.

**CHALLENGES**
Families and youth both viewed the needs of CYSHCN as unique and often requiring a greater number of resources. Therefore, many of the reported barriers which many families face in accessing health care, such as transportation, not knowing where to go or who to see, and insurance affordability create an even greater challenge to families with CYSHCN. Interviews with key informant providers serving the CYSHCN population also reported that a significant number of community-based services were “harder than you would expect” for CYSHCN and families to obtain.

Barriers to accessing services are familiar and remain substantial. The vision of a community-based, family-centered, coordinated, culturally competent system of care for CYSHCN and their families remains elusive. More than half of the families and youth participating in this needs assessment depend on public programs, such as Medicaid and All Kids, to help pay for needed services and struggle to find adequate transportation to access needed specialty care. Despite outreach efforts by various state agencies, some families remain uninformed about what services are available and how they can access them for their CYSHCN. Lack of sufficient care coordination resources is a common theme.
This needs assessment brought further attention to the growing diversity of the state and the additional challenges for this diverse population. We focused on the Hispanic population in one area of the state, but it is likely that their experiences are reflective of this population throughout the state. Many of these individuals are new immigrants, thus, the issues that were dominant for all the families participating in this needs assessment are nearly overwhelming for these families. Further, language and cultural barriers add a layer of complexity that creates a sense of isolation and helplessness. The special needs of this rapidly growing population in Alabama are primarily community-level needs that must be addressed by the communities.

The needs assessment process is the first step in developing strategies and strengthening systems of support to reduce these barriers and create better access for CYSCHN and their families. National efforts at health care reform may help some families by eliminating insurers’ ability to deny coverage for pre-existing conditions or to cap the amount they will pay over a child’s lifetime for a given condition or conditions. State efforts to attract and retain health care providers in the more rural areas of the state should be a priority to improve access to care for all citizens, including CYSCHN. Finally, most improvements in the system must occur at the community level. There must be outreach efforts by local and state agencies to assure that all families are aware of services that are available and that families receive the needed assistance to coordinate the array of services necessary for most CYSCHN.