

Statewide Five-Year Maternal and Child Health Needs Assessment

ALABAMA

Fiscal Year 2014-15

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



From the general report prepared by:

- Bureau of Family Health Services, Alabama Department of Public Health
- Children's Rehabilitation Service, Alabama Department of Rehabilitation Services

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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), a division of the Alabama Department of Rehabilitation Services.

The actual submission from Alabama results from a collaborative process with the Alabama Department of Public Health and covers all Title 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 highlight findings specific to children and youth with special health care needs.

A summary 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 2015.

For any additional questions about the CYSHCN portion of the Alabama Needs Assessment, please contact Lolita McLean, Children's Rehabilitation Service, at (334) 293-7133 or 1-800-441-7607.



Children's Rehabilitation Service is a division of the
Alabama Department of Rehabilitation Services

CRS Executive Summary

2015 Title V Maternal and Child Health Needs Assessment

Report of Findings for Alabama's Children and Youth with Special Health Care Needs and their Families
Alabama Department Rehabilitation Services, Children's Rehabilitation Service
Completed by UAB School of Public Health, Department of Health Care Organization and Policy
May 2015



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I. Introduction

As part of the 2015 Title V Maternal and Child Health (MCH) Needs Assessment, Children's Rehabilitation Service (CRS) entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB) to plan, facilitate, analyze, and report on data collected from children and youth with special health care needs (CYSHCN) and their families. The methods used and results obtained are summarized below. Individual, in-depth reports by method are available through CRS. All data collection instruments were designed through a joint effort between UAB and CRS. CRS was responsible for marketing efforts for the needs assessment as well as participant recruitment for surveys, focus groups, and key informant interviews. UAB facilitated the focus groups and key informant interviews, performed all analyses, and developed final reports.

II. Methods

Information compiled from national surveys, programmatic sources, and previous needs assessments were also considered by CRS and are reported elsewhere. The data described in this report were collected to capture the perceptions of youth with special health care needs (YSHCN), families with CYSHCN, and service providers across the state to add to the knowledge base and to assist in identifying needs specific to these populations. Bringing these two sources of data together allows CRS to consider the issues identified and the general findings across broad cultural and socioeconomic groups. All methods were based on previous instruments, past experience, best practice in instrument development and data collection, the new guidance document for the MCH Block Grant/Needs Assessment, and areas of interest identified by an internal needs assessment leadership team at CRS. Each method is described briefly below.

- A.** The Family Survey was disseminated in online and hard copy formats in English, Spanish, and Korean. Respondents included families living in Alabama who either have or care for CYSHCN ages birth to 25 years.
 - i.** There were 851 responses from 61 of 67 counties.
 - ii.** Respondents were primarily mothers of CYSHCN; white or black, and non-Hispanic.
 - iii.** Strengths:
 - Sample size and survey demographics suggest that respondents were representative of the population of families with CYSHCN across Alabama counties and rural versus urban areas.
 - Responses provide extensive and powerful information to guide the identification of needs and potential solutions.
 - iv.** Limitations:
 - Future endeavors should consider opportunities to increase the number of survey responses and to increase diversity of children and youth across functional levels and disability/special health care need type of CYSHCN.

- B.** The Provider Survey was disseminated in online and hard copy formats in English, focusing on primary care providers for CYSHCN in the state.
 - i.** There were 32 respondents in total, but only 15 were primary care providers.
 - ii.** Respondents were from 10 of 67 counties; five of these counties are designated rural and five are designated urban.
 - iii.** Strengths:
 - The survey instrument was a modification of two standardized national surveys used to measure medical home and support for transition for CYSHCN (Medical Home Index – Short Version and Medical Home Health Care Transition Index). Though a direct comparison with these tools could not be made due to modifications necessary for a project of this type, the indicators and domains were the same, as were the response choices. This allowed for approximations and general comparisons with national data.
 - Findings are most-appropriately considered trends that contribute to the identification of needs and potential solutions.

- iv.** Limitations:
 - Sample size was too small for any advanced statistical analyses.
 - Results are not generalizable to the Alabama primary care providers for CYSHCN.
- C.** The Youth Survey was disseminated in online and hard copy formats in English and Spanish. Respondents were YSHCN living in Alabama ages 12 to 25 years.
 - i.** There were 248 respondents from 53 of 67 counties.
 - ii.** Respondents were mostly ages 12-18 years; white or black, non-Hispanic; and with less than a high school education or still in middle/high school.
 - iii.** Strengths:
 - The sample included representation across Alabama counties and rural versus urban areas.
 - Responses provide extensive and powerful information to guide the identification of needs and potential solutions.
 - iv.** Limitations:
 - Sample size was fairly small.
 - Results may not be generalizable to Alabama YSHCN.
- D.** Key Informant Interviews were facilitated with individuals identified as having expert knowledge of the needs of CYSHCN and their families and the system of care that serves them.
 - i.** Twenty individuals participated in key informant interviews with UAB faculty, staff, or doctoral students.
 - ii.** Participants included representatives from local CRS offices, parents of CYSHCN, social workers, nurses, special educators, health care providers, and representatives from other organizations providing care to CYSHCN and their families.
 - iii.** Strengths:
 - Key informant interviews were facilitated with representatives from coverage areas served by each CRS local office. Participants engaged with the interviewer and added richness to the discussion of maternal and child health issues in the state.
 - Respondents provided keen insights and information to guide the identification of needs and potential solutions.
 - iv.** Limitations:
 - As is true of all qualitative interview data, results are not generalizable to members of the population or to other states/regions.
- E.** Focus Groups were facilitated with representatives of Alabama's families of CYSHCN and YSHCN.
 - i.** A total of five focus groups were facilitated addressing families with CYSHCN, fathers of CYSHCN, Hispanic families of CYSHCN, and YSHCN (supplemented with additional youth interviews).
 - ii.** Focus groups were conducted in Birmingham, Gadsden, Montgomery, Selma, and Dothan.
 - iii.** Strengths:
 - Participants actively engaged in conversation and added a great deal of richness to the discussion of issues and needs for CYSHCN and their families.
 - Findings likely represent broad viewpoints that exist for Alabama's CYSHCN and their families.
 - Respondents provided extensive and powerful information to guide the identification of needs and potential solutions.
 - iv.** Limitations:
 - As with all qualitative focus group data, findings are not generalizable to all members of the population or to other states/regions.
 - The YSHCN focus group had to be supplemented with additional structured interviews due to low attendance.

- Most of the participants were likely a convenience sample as funding and time limitations precluded broad community recruitment. As CRS is such an integral part of the system of services for CYSHCN and their families, especially in smaller, rural areas, most focus group participants received services themselves through the agency, had received services in the past, or had children who were currently receiving services.

III. Needs Identified Across All Methods

Data from across all methods were analyzed and compared to identify needs that emerged for Alabama's CYSHCN and their families. The following chart displays needs that emerged from across all data sources. These needs are not presented in any particular order. A plus sign (+) indicates data sources that specifically addressed the issue and where results confirmed the need. While other CRS data sources also verify these needs, these data are not presented in the chart.

Needs identified for CYSHCN and their families by data source

Priority Need/Issue	Data Source				
	Family Survey	Provider Survey	Youth Survey	Focus Groups	Key Informant Interviews
Lack of or inadequate supports for transition to adulthood	+	+	+	+	
Lack of or inadequate access to medical homes	+	+	+		
Lack of or inadequate access to health and health-related services, including allied health therapies, mental health/behavioral services, and specialty care	+			+	+
Lack of or inadequate access to community services and supports, including recreational opportunities, child care, out-of-school care, respite care, and family support	+			+	+
Families need assistance to identify providers and resources and to navigate the system of care	+			+	+
Support shared decision-making and partnerships between families and health and health-related professionals	+	+		+	
System of care is not perceived as sensitive and culturally competent across diverse populations				+	
Increase family and youth involvement and participation in advisory groups, program development, policy-making, and system-building activities	+		+	+	
Inadequate insurance, including cost and benefit coverage issues	+			+	+
Lack of awareness of state health insurance-related issues that may impact CYSHCN and families, including ACA and Medicaid reform (RCOs)	+			+	
Insufficient and inappropriate preparation and planning for emergency and disaster situations	+		+	+	
Lack of or inadequate information about healthy habits and behaviors, including recreation, physical activity, nutrition, sexual health, and risk behaviors	+		+	+	

Priority Need/Issue	Data Source				
	Family Survey	Provider Survey	Youth Survey	Focus Groups	Key Informant Interviews
YSHCN are not meeting guidelines for physical activity and nutrition			+	+	
Dissatisfaction with special education services, IEP process, and receipt of allied health therapies in school	+			+	
Lack of or inadequate transportation for accessing health and community services			+	+	+

IV. Prioritized Needs For CYSHCN and Their Families

In March 2015, CRS convened a final meeting of its statewide Needs Assessment Advisory Committee to assist with the prioritization of identified needs for CYSHCN and their families. In addition to other quantitative data available to the CRS, data from each of the collection methods described in this report were presented to the group. The entire list of needs was also presented for consideration, and participants were divided into small groups to discuss findings and needs based on their experiences.

A. Process to Obtain Needs Rankings

- Individual group members rated each need according to three separate criteria:
 - “Importance” refers to the size, scope, and urgency of the need/issue.
 - “Feasibility” refers to a level based on these questions: Is there a solution? Can we realistically make progress?
 - “Resources” refers to the level of expertise, time, and funding to address the need, either at CRS and/or through partnerships with other agencies and organizations.
- Scoring Scale for rating needs:
 - 1 = Low 2 = Low-Medium 3 = Medium 4 = Medium-High 5 = High
- Individual ratings for criteria scores were summed to yield total score for each need.
- Total scores were summed for entire group to assign rank order for needs.
- Ties were broken by total scores for individual criteria in the following order:
 - 1. Feasibility 2. Importance 3. Resources

The following tables show rank-ordered needs for each population group as rated and ranked by participants at the statewide advisory meeting.

B. Ranked Needs by Population Domain

Overall Rank	Priority Need/Issue	Total Score
	Lack of or inadequate supports for transition to adulthood*	
	Lack of or inadequate access to medical homes*	
1	Families need assistance to identify providers and resources and to navigate the system of care	332
2	Support shared decision-making and partnerships between families and health and health-related professionals	314
3	Insufficient and inappropriate preparation and planning for emergency and disaster situations	313
4	Increase family and youth involvement and participation in advisory groups, program development, policy-making, and system-building activities	309
5	Lack of or inadequate information about healthy habits and behaviors, including recreation, physical activity, nutrition, sexual health, and risk behaviors	306

6	Lack of awareness of state health insurance-related issues that may impact CYSHCN and families, including ACA and Medicaid reform (RCOs)	304
7	Dissatisfaction with special education services, IEP process, and receipt of allied health therapies in school	301
8	Lack of or inadequate access to health and health-related services, including allied health therapies, mental health/behavioral services, and specialty care**	291
9	Inadequate insurance, including cost and benefit coverage issues	282
10	YSHCN are not meeting guidelines for physical activity and nutrition	281
11	Lack of or inadequate access to community services and supports, including recreational opportunities, child care, out-of-school care, respite care, and family support	276
12	System of care is not perceived as sensitive and culturally competent across diverse populations	269
13	Lack of or inadequate transportation for accessing health and community services	256
14	Lack of or inadequate access to mental health services***	114

**These needs were not rated or ranked by group as CRS will address these through national performance measures*

***One group separated mental health services from this need and established it as another need*

****Added by one group only; separated from another need*

V. Results Summary

The remainder of this executive summary provides a general overview of results across method. For more detailed results and more in-depth reporting by method, please refer to the method-specific reports which are also available through CRS.

A. Medical Home

- Based on a series of questions modeled after the National Survey of Children with Special Health Care Needs, 59.3% of family survey respondents met the definition for receiving health care for their CYSHCN in a medical home.
 - 90.1% - have personal doctor or nurse
 - 84.7% - usually or always felt like a partner with provider
 - 88.2% - believed provider was usually or always sensitive to family values and customs
 - 97.2% - got an interpreter if needed one
 - 91.2% - were very or somewhat satisfied with communication among providers
 - 84.0% - had no problems getting referrals if needed
- Providers were asked questions modified from the Medical Home Index-Short Version (Center for Medical Home Improvement, 2006).
 - Mean score overall for level of “medical homeness” was 2.9 which is considered as “proactive pediatric primary care” on a 1-5 scale ranging from responsive to completely comprehensive
 - Lowest mean scores were noted for indicator areas “Supporting the Transition to Adulthood” and [providing opportunities for] “Family Feedback” [to the practice].

B. Transition to Adulthood

- Based on a series of questions modeled after the National Survey of Children with Special Health Care Needs, 5.7% of family survey respondents with youth ages 16-25 years met the definition for receiving necessary supports for transition to adulthood.
 - 65.0% - Provider has discussed needs as youth becomes an adult.
 - 52.2% - Provider usually or always encourages youth to take responsibility for health needs.
 - 15.5% - Someone has encouraged planning for getting and keeping health insurance into adulthood.
 - 25.0% - Someone has encouraged finding an adult physician.

- Providers were asked questions modified from the Medical Home Health Care Transition Index (Center for Medical Home Improvement, 2006).
 - Mean score overall for level of support for transition was 3.75, which is considered as “responsive” (between Level 2 – partial and Level 2 – complete) on a 1-8 scale ranging from basic to completely comprehensive.
 - Lowest mean scores were noted for indicator areas “Transition preparation” and “Identification of transitioning youth”.
 - Few practices (26.7%, 4 of 15) reported they develop a written transition plan with families and youth.
 - Less than 20.0% of practices reported that they have a uniform transition and transfer of care policy.
 - Few practices (26.7%, 4 of 15) indicated that youth are seen without their family members for portions of encounters after age 14.
- Based on a series of questions modeled after the National Survey of Children with Special Health Care Needs, 20.4% of youth survey respondents ages 16 years and older met the definition for receiving necessary supports for transition to adulthood.
 - 65.6% - Provider had discussed needs as youth becomes an adult.
 - 60.2% - Provider usually or always encouraged youth to take responsibility for health needs.
 - 68.7% - Provider “always” or “frequently” helped youth feel involved or included in health care decisions.
 - 55.0% - Youth had opportunity to speak with provider privately during regular check-ups.
- Family focus group participants reported that providers typically did not discuss transition and that they sought out these services themselves. Participants also stated that in their experience, planning for the future was solely focused on financial and legal services rather than health care.
- Youth focus group and structured interview participants indicated that they were dissatisfied with the supports available for transition and were not aware of a formal transition plan in place for them. They noted that they have clearly defined plans for future both academically and professionally, but that these plans are based on their families or themselves, not provider discussions. Youth expressed a desire for more individualized supports for their future plans versus provider perceptions of what their plan should be.

“It’s kind of that double standard, ‘Oh, because you’ve got a disability, you’re not free to make your own choices. You’re not free to live your life,’ so to speak. People are always trying to dictate how they think a person with a disability should act or what they should be like. And you can’t put us in a box like that... – a lot of people that don’t know, they feel like we all act the same and all think the same way and that’s not the case.”

- Youth interview participant

C. Medical and Health-Related Services

- Family survey respondents were provided a list of services and asked to indicate their experiences in obtaining the service for their child or youth. Unmet need for services was defined either as the inability to obtain a needed service or as having obtained the needed service, but not being satisfied with it.
 - 34.7% reported unmet need for at least one health or health-related service
 - The top five reported unmet health service needs were:
 - Occupational therapy
 - Speech therapy
 - Physical therapy
 - Mental health/behavioral services
 - Specialty health care
 - The top three most frequently reported barriers to obtaining services were:
 - Providers not available

- Insurance did not cover services or providers
 - Did not know where to go or who to see
- Key informants rated the following services as most the difficult for families in their communities to obtain:
 - Mental health/behavioral services
 - Specialty health care
 - Occupational therapy
 - Speech therapy
 - Physical therapy
 - Nutrition counseling
- Family focus group participants noted limitations to accessing specialty care services other than CRS clinics in regions outside of the state's larger metropolitan areas. They also reported that travel distances to reach these specialists were a burden. Families discussed challenges they had experienced with a lack of provider knowledge related to treating CYSHCN and limited time with providers to sufficiently address their needs.

D. Other Community Services and Supports

- Family survey respondents were provided a list of services and asked to indicate their experiences in obtaining the service for their child or youth. Unmet need for services was defined either as the inability to obtain a needed service or as having obtained the needed service, but not being satisfied with it.
 - 32.4% reported unmet need for at least one community-based service
 - The top five reported unmet community-based service needs were:
 - Recreational opportunities
 - Good quality summer/out-of-school care
 - Special Education services (3 to 21 years)
 - Respite care
 - Support for families (training, support groups)
 - The top three most frequently reported barriers to obtaining services were:
 - Did not know where to go or who to see
 - Providers not available
 - Services too expensive
- Key informants rated the following services as the most difficult for families in their communities to obtain:
 - Transportation assistance for medical or dental appointments
 - Good quality summer/out-of-school care
 - Respite care
 - Good quality child care/day care
 - Good quality after school care
- Key informants were also asked an open-ended question to discuss the top-three “biggest issues” or “greatest needs” for families in their communities (including health, health-related, and community-based services). Overall, the issues mentioned most frequently were:
 - Transportation
 - Respite Care
 - Child care (daycare, summer/out-of-school care, and after school care combined)
- Family focus group participants reported a need for increased access to Early Intervention services and respite care, either through more visits or in a broader geographic distribution. Families frequently discussed the need for child care for CYSHCN, especially care that was high quality and affordable. Some families noted that more support groups or advocacy groups were needed. Recreational opportunities were reported in some areas of the state, but overall, participants indicated that these opportunities were not meeting the needs of families.

"I don't know that I've ever seen another child with a hearing aid besides just maybe on Facebook and these friends that we did have, this one couple we met, they've moved. So I think the support groups are lacking. And being able to talk to other parents ... about what's going on."

- Family focus group participant

E. System of Care

- Data across all methods suggested that the system of care for CYSHCN and their families was difficult to navigate.
- Through surveys and focus groups, families indicated that they did not feel equipped to navigate the system of care on their own. Key informants also reported navigating the system of care as a significant issue and barrier to obtaining services in local communities.
- Focus group participants expressed a lack of knowledge about eligibility for services and available health and community services. CRS was viewed as a helpful facilitator in this process.
- Hispanic focus group participants and those who received Medicaid discussed having experienced stigma, bias, and prejudice during some interactions with the health care system.

"I feel like you're walking uphill all the time because you just kind of have to search and fight for the information where it's not, you know, sometimes I feel like you have to fight for things a lot, for services and the information."

- Family focus group participant

F. Emergency Preparedness

- Family survey respondents were asked a series of questions about their level of preparedness for emergencies and disasters. A definition for "emergency" was not provided, leading to the possibility that respondents considered only medical emergencies instead of natural disasters or other emergency situations.
 - Over two-thirds of all respondents (67.2%) indicated they had a plan in place to cover their child or youth's needs in an emergency, and over half (52.0%) said they had a preparedness kit that would meet their child's needs.
 - Less than one-third (31.8%) of all respondents said that they had an up-to-date copy of their child or youth's medical records (digital or paper) on-hand if they had to evacuate to another city or state during a disaster.
 - Respondents with children and youth who had less independence related to their functional skills were less likely to report they were "very sure" the school could take care of their child's needs and more likely to report they "did not know" or "did not think" the school could meet their child's needs compared to respondents whose children had more independence related to their functional skills.
 - "Developing an emergency preparedness plan for my family" and "creating an emergency preparedness kit that will meet my child(ren)/youth's special health care needs" were the third and fifth most frequently reported topics about which family survey respondents would like to have more information.
- Few family or youth focus group/interview participants reported having a plan, written or otherwise, for emergencies related to natural disasters. Very few also indicated that they had an emergency preparedness kit that would meet their (youth) or their child's health-related needs in an emergency or natural disaster. Some participants viewed their experience of managing medical emergencies as strengthening their resilience to handle disaster situations, and several identified their social worker at CRS as a primary point of contact in the event of any emergency. The majority of participants said they had not thought about emergency preparedness in the context of natural disasters and expressed a desire for more knowledge and awareness about these issues with coordination specific to their families' needs.

“I really don’t think that’s something that I’ve really thought about. It would be helpful maybe to have some information or a seminar or something, saying have you thought about this?”

- Family focus group participant

“In my case, I have never had an emergency, but I think that if I had one my social worker has told me that when something like that occurs, I can call her and she will call the emergency service of the community.”

- Youth structured interview participant

G. Financial/Insurance

- Family focus group participants reported that having a CYSHCN results in high out-of-pocket costs, and that these expenses are not limited to medical costs; financial assistance for power/utility bills and other costs of living was reported as a need. They also indicated that insurance coverage limitations and high out-of-pocket costs hindered access to receiving services.
 - o There was a lack of awareness about Alabama Medicaid’s pending transformation/reform to Regional Care Organizations (RCOs).
 - o While awareness of the Affordable Care Act (ACA) was high, focus group participants were uncertain of its impact. Families reported mixed experiences; some families saw premium increases while others saw premium decreases or no changes.
- Youth focus group and interview participants expressed a general lack of knowledge of who pays for their health care as well as details about their coverage and benefits.
- Hispanic focus group participants’ knowledge of All-Kids (Alabama’s Children’s Health Insurance Program), Medicaid, and the Affordable Care Act was limited or absent. There was confusion among this population about what options are available to them.
- Most family survey respondents reported that their child or youth was currently covered by insurance – about 3.0% were uninsured. Approximately 8.0% reported that there had been at least some time during the previous 12 months in which their child or youth was uninsured.
 - o Over three-fourths of respondents (76.9%) indicated their child or youth currently had public insurance, while more than one-third (36.6%) reported private insurance.
- Family survey respondents were asked about their knowledge of upcoming changes to the Alabama Medicaid system (RCOs) and their perception of how these changes might impact their family.
 - o Most survey respondents knew little about the changes, including those who said they currently received Medicaid (86.6% of the overall sample and 84.3% of Medicaid recipients reported they knew “nothing” about these changes).
- Respondents were also asked about their knowledge of the ACA and how this law might impact their family.
 - o More than half (66.1%) reported they knew “only a little” or “nothing” about the ACA.
 - o Most respondents (62.3%) indicated they did not know or were not sure how the ACA might impact their family. Among those who indicated a direction of impact, about one-fifth (21.2%) indicated their family would be worse off as a result of the ACA.

H. Healthy Habits and Activities among YSHCN

- Youth focus group and interview participants reported that they received health information from their physicians, family members, therapists, and trainers. They were aware that having healthy friendships/dating relationships; preparing for safe sexual encounters; and avoiding risky behaviors such as smoking, drugs, or drinking were important for staying healthy. Youth indicated that they sought out information related to these issues from their parents, friends, the internet, and their school; they had not discussed these topics with health providers.
- Youth survey respondents were asked a series of questions related to their social/recreational activities and healthy habits.
 - o The top-four most frequently reported social/recreational activities (listen to music; watch television; use computer, tablet, smartphone for games, Internet, social media; text or message with friends) were similar to what might be expected of youth in general. However, all of these are sedentary activities.

- o More than a quarter of respondents (27.2%) reported that they had not been physically active or exercised at all over the previous week.
- o Only 8.9% of youth met the CDC recommendations for physical activity (60 minutes per day each day) based on reported physical activity during the preceding week. The most commonly reported frequency of exercise for youth was no days. This finding is not entirely explained by functional skill levels of the youth based on reported assistance levels for daily living skills. It is also inconsistent with current support for adapted physical activity and recreational opportunities for individuals with disabilities.
- o Fruit and vegetable consumption was low overall; however, 64.0% of youth reported eating a fruit or vegetable at least one time per day over the preceding week.
- o “How I can be healthy (exercise, eat well, take care of myself)” and “Recreational activities” were the fourth and fifth most frequently reported topics about which youth survey respondents would like to have more information.
- “Recreational activities” and “healthy behaviors” were the second and third most frequently reported topics about which family survey respondents would like to have more information.

“Being healthy is very important because it’s already a struggle being a person with a disability. And by not being healthy, you’re aiding that struggle – [being healthy] it helps you overcome some of your obstacles that you have being a person with a disability. It helps you be independent ...”

- Youth structured interview participant

“For people with disabilities, I don’t feel like it’s talked about at all because a lot of people assume that we can’t have sex anyway.”

- Youth structured interview participant
[speaking about discussing sexual health and methods to prevent pregnancy and/or sexually-transmitted infections with providers]

I. Education

- Special education services was number three on the list of most frequently reported unmet needs for community-based services.
- Family focus group participants expressed dissatisfaction with the individualized education plan (IEP) process and with receipt of allied health therapies in school.
- Hispanic family focus group participants indicated a need for school personnel with whom they can communicate.

“I’m almost scared of the process because you have to fight....It scares me to think that they’re pushing back. Your child doesn’t need that when I just felt like it’s going to be an uphill battle.”

- Family focus group participant
[speaking about the IEP process]

J. Transportation

- Data related to transportation (and the lack of transportation) as a need were variable across data sources.
- Focus group participants noted transportation as a concern, especially in rural areas and especially given the long distances some participants had to travel to obtain specialty services. Though they did report that some resources exist, these were not perceived to be adequate to meet their needs. Some participants reported using public transportation, but indicated that where public transit exists, limited schedules and routes often hindered families and youth's abilities to move around their environment. When public transit was unavailable, participants reported using a variety of alternative modes of transportation including: taxis, Greyhound buses, friend or neighbors' cars, and rental cars. Some families noted that the lack of quality public transportation in metropolitan areas prevented them from being able to reach providers and services "across town". High gas prices and costs to maintain vehicles were also considerations for participants. Youth respondents expressed a desire to learn to drive. They indicated feeling dependent upon parents or friends to "get around." Though some youth reported having had seamless, positive experiences with the available services in the state for learning to drive adapted vehicles, others discussed experiencing challenges accessing these services.
- Key informants rated transportation as the hardest community-based service for families in local communities to obtain. They also listed it as the number one barrier to obtaining health, health-related, and community-based services. Informants reported lack of transportation as one of the three "biggest" barriers families in their communities faced and also indicated that transportation was one of the three "greatest" needs for families in their communities.
- Approximately 11.0% of family survey respondents reported an unmet need for transportation assistance. Roughly 5.0% of respondents indicated lack of transportation as a barrier to receiving health, health-related, and community-based services.

"We have very limited public transit. And it's only available Monday through Friday and you do have to call in advance. And there's only a couple of buses that I think they actually have that are wheelchair accessible. You have to call in advance. So if you have an emergency and you need to get to a doctor and you have a person that's in a wheelchair, unless you have a friend or a neighbor or someone, you're kind of out of luck with that."

- Family focus group participant

CRS Family Survey

Report of Survey of Families of Children and Youth with Special Health Care Needs
Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
A portion of the 2015 Title V Maternal and Child Health Needs Assessment
Completed by UAB School of Public Health, Department of Health Care Organization and Policy



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I. Introduction

As a part of the 2015 Title V Maternal and Child Health (MCH) Needs Assessment, the Alabama Department of Rehabilitation Services, Children's Rehabilitation Service (CRS) entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB) to develop, analyze, and report on a survey of Alabama families that have children and youth with special health care needs (CYSHCN). Survey design was a partnership between UAB and CRS. CRS was responsible for all marketing and recruitment related to the survey. UAB performed all analyses and developed final reports.

NOTE: Questions related specifically to other MCH population groups (women, women of child-bearing age, children, and their families) were not a part of the CRS Family Survey. Perspectives of these groups were captured by the Title V MCH Program, located in the Bureau of Family Health Services in the Alabama Department of Public Health. A separate report is available related to these groups). The final Alabama 2015 MCH Needs Assessment Report includes perspectives from all MCH populations in the state, including CYSHCN and their families.

II. Methods

A. Survey Design and Format

UAB and CRS developed a survey based on previous instruments, best practices in survey design, the new guidance documents for the MCH Block Grant/Needs Assessment, and areas of interest identified by an internal needs assessment leadership team at CRS. The survey was available online and in hard copy formats in English, Spanish, and Korean. UAB developed the survey in the survey design and collection software Qualtrics, and the URL was linked to a user-friendly domain name purchased through a third-party vendor. The link supported easier marketing and dissemination (www.CRSfamilysurvey.com). Hard copy survey responses were hand entered by staff in the UAB Evaluation and Assessment Unit, with at least 10% recheck by an alternate staff member to ensure accuracy of data entry. Survey responses were anonymous, and the survey was available for completion in the summer and early fall of 2014.

B. Marketing and Recruitment

CRS was responsible for all marketing and recruitment efforts for the survey. Strategies included hard copies made available in CRS clinics, postcards with the survey link provided in local CRS offices, hard copies and postcards provided at focus groups (also conducted as a part of the overall needs assessment methods), social media marketing campaigns, and sharing of the survey link via partner agency/organization communication methods.

C. Analyses

All analyses were conducted by UAB using Stata statistical software.

III. Demographics of the Sample

- N = 851
- At least 1 response from 61 of Alabama's 67 counties
- Most respondents completed the survey in hard copy format (73.7%) and in English (96.6%).
- Rural versus Urban designations were assigned based on two methods:
 1. Whether the county lies within a metropolitan statistical area (MSA) (U.S. Office of Management and Budget definition), and
 2. Alabama Rural Health Association definition ("What is Rural?")
- Both methods are discussed on the following website: arhaonline.org/about-us/what-is-rural/
- Though the MSA definition is recommended by the U.S. Office of Management and Budget, the alternate classification was also incorporated in analyses as it has been used by CRS in previous needs assessment reports. These methods differ in that more Alabama counties are designated "urban" according to MSA inclusion as compared to the Alabama Rural Health Association definition.
- Using the MSA designation, the majority of respondents were from urban counties (61.4%). Using the alternative classification, the percentages of rural versus urban residencies were similar (49.9% and 50.1%, respectively).

Survey format and language

	N	%
Survey Format		
Online	224	26.3
Hard Copy	627	73.7
Survey Language		
English	822	96.6
Spanish	24	2.8
Korean	5	<1.0

Participants by county type, based on MSA definition

County Type	N	%
Rural – not in MSA	281	38.5
Urban – in MSA	448	61.4

Participants by county type, based on “What is Rural?” definition

County Type	2015		2010	
	N	%	N	%
Rural	364	49.9	504	46.6
Urban	365	50.1	577	53.4

- Respondents were primarily mothers of CYSHCN (77.9%).
- Educational levels were generally well-balanced across categories. Approximately 60.0% had some training/education beyond high school.
- Over half of respondents self-identified as “white” (53.0%) while 38.4% self-reported as “black.”

Respondent characteristics

Respondent Characteristic	N	%
Relationship to CYSHCN		
Mother	553	77.9
Father	48	6.8
Grandparent	66	9.3
Other Relative/Other	43	6.1
Highest level of education		
Less than high school	80	11.5
High school diploma or GED	194	27.9
Some college (did not graduate)	146	21.0
Vocational training, trade school, Associate’s degree	131	18.8
Bachelor’s degree or higher	144	20.7
Race/ethnicity		
Hispanic	44	4.2
Asian	11	1.5
Black	273	38.4
White	376	53.0
Other/Multiple	21	2.9

- The mean age of respondents' CYSHCN was 10.6 years.
- Analyses for future plan discussions and transition to adulthood were limited to respondents with youth ages 12-25 years and 16-25 years (see these sections of the report).
- Functional levels for children and youth were determined based on a series of questions modified from the standardized assessment, Functional Independence Measure (FIM). Since this tool is intended for clinicians, the items and language of the measurement scale were modified to make it easier for respondents to understand and use. The purpose of the FIM is to provide a uniform system of measurement for disability based on the International Classification of Impairment, Disabilities and Handicaps. This tool indicates the amount of assistance required for an individual to carry out activities of daily living.
- Functional levels were calculated for children and youth ages 5-25 years using the modified instrument. A total of 13 daily living skills were presented, with 11 applied to ages 5-25 years and two additional skills reserved for youth ages 16-25 years.
- Respondents considered each item and selected a score that matched the level of assistance needed by their CYSHCN (or oldest CYSHCN if they had more than one) based on the following scale:
 - 1 = Can do by themselves with no help
 - 2 = Can do by themselves, but needs a little more time or to use equipment (braces, wheelchair, walker, bath seat)
 - 3 = Can do by themselves, but needs someone to watch for safety or to give cues
 - 4 = Mostly can do, but needs just a little help from someone
 - 5 = Can do some, but needs a good bit of help from someone
 - 6 = Can do a little, but needs a lot of help from someone
 - 7 = Can't do at all - someone else must do it for them
- The 50th percentile score was calculated for overall functional levels among children and youth ages 5-25 years to identify groups with more independence (mean scores below the 50th percentile) vs. those with less independence (mean scores above the 50th percentile) overall. This designation was incorporated into select analyses (see next section).
- Daily living skills were grouped into the following daily living skill areas:
 - Self-care skills:
 - Bathing/Dressing, Feeding self/Drinking, Take care of toileting, and Using equipment or braces
 - Motor skills:
 - Moving his/her body from one place to another and Using hands and arms
 - Cognitive skills:
 - Learning and using new information and Focusing and keeping attention
 - Social-emotional skills:
 - Keeping control over emotions and behaviors and Interacting or connecting socially with others
 - Communication skills:
 - Using spoken language to communicate with others
- Lower scores – by item, skill area group, or overall – indicated more independence. Mean scores were calculated for each item, skill area group, and overall for children ages 5-25 years. A percentage completion of the total possible score was calculated for each skill area group by dividing the mean for the area by the total points possible for the area and converting it to a percentage. The higher the percentage, the higher the score and the more assistance required to complete skills (less independence).
 - Respondents' CYSHCN had highest levels of independence with motor skills and lowest levels of independence with cognitive skills.

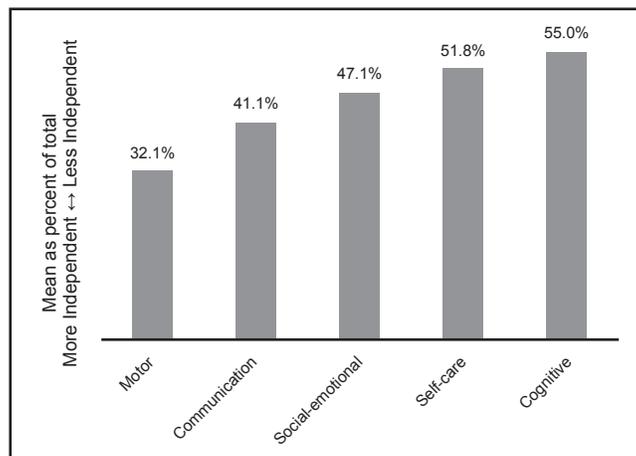
Child/youth with special health care needs characteristics

Child/Youth Characteristic	N	%	Mean
Age			
0-4 years	100	14.6	10.6 years
5-25 years	585	85.4	
12-25 years	325	47.4	
16-25 years	158	23.1	
Functional level - overall (ages 5-25)			
More independent (below 50 th percentile)	167	46.5	-
Less independent (above 50 th percentile)	192	53.5	

Functional Skill Levels (Scale 1 – 7, 1=independent; 7=dependent)	Range of Possible Scores	Mean
Functional Skills (age 5-25 years)	1-7, each	
Bathing / Dressing		3.5
Feeding self / Drinking		2.6
Take care of toileting		3.3
Moving his/her body from one place to another		2.5
Using hands and arms		2.1
Using equipment or braces		3.6
Taking medicines ¹		4.3
Learning and using new information		4.0
Managing money ¹		4.9
Focusing and keeping attention		3.8
Keeping control over emotions and behaviors		3.5
Interacting or connecting socially with others		3.1
Using spoken language to communicate with others	2.9	
Overall functional level (age 5-25 years)	11-77	35.8
Motor skills	2-14	4.5
Communication skills	1-7	2.9
Social-emotional skills	2-14	6.6
Self-care skills	4-28	14.5
Cognitive skills	2-14	7.7

¹Included for youth ages 16-25 years only

Functional independence levels by activity of daily living skills areas calculated by dividing mean score by total score possible for each area



IV. Findings

A. Health and Health-Related Services

- Respondents were provided a list of services and asked to indicate their experiences in obtaining the service for their child or youth. Respondents selected one of the following responses:
 - “Did not need this”
 - “Needed, but could not get”
 - “Got it, but was not satisfied”
 - “Got it, and was satisfied”
 - “Do not know”
- Among families who indicated a need for the service, responses of “Needed, but could not get” or “Got it, but was not satisfied” were considered unmet need for that service.
- Over one-third of respondents indicated an unmet need for at least one of the health and health-related services presented.
- Unmet needs ranged from 2.6% for hearing aids to 15.8% for occupational therapy.
- The highest levels of unmet need were reported for health-related therapies (PT, OT, Speech) and mental health/behavioral services.
- In contrast to previous needs assessment and data from other methods employed during the current needs assessment (focus groups, key informant interviews), respondents from rural areas were statistically significantly less likely to report unmet needs for health and health-related services compared to urban respondents. This finding held true using both definitions of rural versus urban county. More assessment is warranted in this area to determine rural versus urban differences in service receipt.
- As could be expected, respondents with children and youth who had functional scores indicating more independence were statistically significantly less likely to report unmet needs for health and health-related services compared to respondents whose children had functional scores indicating less independence. Parents of children and youth with lower functional levels were more likely to report unmet needs for health and health-related services.
- The most commonly-reported barriers to obtaining health and health-related services were:
 - “Providers not available”
 - “Insurance didn’t cover services or providers”
 - “Did not know where to go/who to see”

Unmet need for health and health-related services, ordered by reported unmet need (highest to lowest)

Service	Number reporting unmet need	Percent reporting unmet need
Any health and health-related service	295	34.7
Occupational Therapy	98	<u>15.8</u>
Speech Therapy	97	<u>15.1</u>
Physical Therapy	85	<u>13.2</u>
Mental health/behavioral services	74	<u>11.8</u>
Specialty health care	61	9.1
Dental care	60	9.2
Vision screening	57	8.6
Developmental screenings	54	8.5
Special Equipment or Braces	51	8.0
Nutrition counseling	44	6.9
Eyeglasses/Contacts	40	6.3
Primary health care	38	5.4
Scoliosis screening	28	4.9
Emergency health care	26	4.0
Hearing screening	24	3.7
Hearing aids	16	2.6

*Underlined and bolded cells indicate services with highest reported levels of unmet need

Unmet need for health and health-related services by rural/urban and functional level

Unmet need for any health and health-related service	Rural vs Urban by MSA definition ¹ N (%)		Rural vs Urban by previous definition ² N (%)		More independent functional level ³ N (%)	
	Rural	Urban	Rural	Urban	Yes	No
Yes	92 (32.7)	189 (42.2)	120 (33.0)	161 (44.1)	49 (29.3)	94 (49.0)
No	189 (67.3)	259 (57.8)	244 (67.0)	204 (55.9)	118 (70.7)	98 (51.0)

¹Chi-square analyses; X=6.51; p=0.011

²Chi-square analyses; X=9.55; p=0.002

³Chi-square analyses; X=14.34; p=0.000

Reported barriers to receiving health and health-related services, in order of most frequently-reported

Barriers	Number reporting unmet need	Percent reporting unmet need
Providers not available	74	11.6
Insurance didn't cover services or providers	65	10.3
Did not know where to go/who to see	65	10.2
Waiting list for services too long	46	7.3
Services too expensive	42	6.7
Hours/location of providers not convenient	42	6.7
No transportation	28	4.6
Can't afford co-pays and deductibles	28	4.5
Work conflict - unable to take time off work	28	4.5
Denied services by provider	26	4.2
No insurance	23	3.8
Difficulty understanding what insurance provides	22	3.6
Missed school days	21	3.4
State policy or administrative barriers	17	2.8
Not satisfied with quality of service or product or training level of provider	16	2.6
Lack of child care	14	2.3
Work conflict - can't afford to lose pay	14	2.3
General communication problems with provider/problems with treatment by provider	10	1.6
Waiting time in offices too long	9	1.4
Language/cultural barriers	5	0.82
Limited choices of providers	4	0.64
Other	29	4.6

B. Community-Based Services

- Respondents were provided a list of services and asked to indicate their experiences in obtaining services for their child or youth. Respondents selected one of the following responses:
 - "Did not need this"
 - "Needed, but could not get"
 - "Got it, but was not satisfied"
 - "Got it, and was satisfied"
 - "Do not know"
- Among families who indicated a need for the service, responses of "Needed, but could not get" or "Got it, but was not satisfied" were considered unmet need for that service.
- Nearly one-third of respondents indicated an unmet need for at least one of the community-based services presented.
- Unmet needs ranged from 2.5% for early intervention to 22.6% for recreational opportunities.
- The highest levels of unmet need were reported for recreational opportunities, respite care, support for families (training, support groups), good quality summer/out-of-school care, and special education services.

- In contrast to previous needs assessment and data from other methods employed during the current needs assessment (focus groups, key informant interviews), respondents from rural areas were statistically significantly less likely to report unmet needs for community-based services as compared to urban respondents. This finding held true using both definitions of rural versus urban county. More assessment is warranted in this area to determine rural versus urban differences in service receipt.
- As could be expected, respondents with children and youth who had functional scores indicating more independence were statistically significantly less likely to report unmet needs for community-based services compared with respondents whose children had functional scores indicating less independence. Parents of children and youth with lower functional levels were more likely to report unmet needs for community-based services.
- The most commonly-reported barriers to obtaining community-based services were:
 - o “Did not know where to go/who to see”
 - o “Providers not available”
 - o “Services too expensive”

Unmet need for community-based services, ordered by reported unmet need (highest to lowest)

Service	Number reporting unmet need	Percent reporting unmet need
Any community-based service	276	32.4
Recreational opportunities	128	<u>22.6</u>
Good quality summer / out-of-school care	96	<u>15.6</u>
Special Education services (3 to 21 years)	89	<u>14.1</u>
Respite care	89	<u>15.9</u>
Support for families (training, support groups)	89	<u>15.7</u>
Good quality after school care	74	11.9
Transportation assistance for medical or dental appointments	66	10.8
Good quality child care / day care	61	9.9
Care coordination / case management / service coordination	49	8.4
HeadStart/Pre-K programs (3 to 5 years)	22	3.5
Early Intervention programs (birth to 3)	16	2.5

*Underlined and bolded cells indicate services with highest reported levels of unmet need

Unmet need for community-based services by rural/urban and functional level

Unmet need for any community-based service	Rural vs Urban by MSA definition ¹ N (%)		Rural vs Urban by previous definition ² N (%)		More independent functional level ³ N (%)	
	Rural	Urban	Rural	Urban	Yes	No
Yes	88 (31.3)	180 (40.2)	119 (32.7)	149 (40.8)	52 (31.1)	94 (49.0)
No	193 (68.7)	268 (59.8)	245 (67.3)	216 (59.2)	115 (68.9)	98 (51.0)

¹Chi-square analyses; $X=5.83$; $p=0.016$,

²Chi-square analyses; $X=5.18$; $p=0.023$,

³Chi-square analyses; $X=11.75$; $p=0.001$

Reported barriers to receiving community-based services, in order of most frequently-reported

Barriers	Number reporting unmet need	Percent reporting unmet need
Did not know where to go/who to see	129	19.9
Providers not available	81	12.6
Services too expensive	64	10.1
Insurance didn't cover services or providers	49	7.8
Waiting list for services too long	44	7.1
Hours/location of providers not convenient	32	5.2
No transportation	31	5.1
Lack of child care	22	3.6
Work conflict - unable to take time off work	20	3.3
State policy or administrative barriers	19	3.1
Denied services by provider	17	2.8
Missed school days	15	2.5
Work conflict - can't afford to lose pay	12	2.0
Not satisfied with quality of service or product or training level of provider	10	1.6
General communication problems with provider/problems with treatment by provider	5	0.81
Language/cultural barriers	3	0.49
Other	26	4.2

C. Medical Home

- Respondents were asked a series of questions that mirror those from the National Survey of Children with Special Health Care Needs in order to determine the extent to which these Alabama children and youth with special health care needs received care in a medical home. In order to meet the definition for receiving care in a medical home, respondents must have met all of the following criteria:
 - Have a personal doctor or nurse for their child/youth
 - "Usually" or "always" felt like a partner with provider
 - Believed provider was "usually" or "always" sensitive to family values and customs
 - Got an interpreter if needed one
 - Were "very satisfied" or "somewhat satisfied" with communication among providers
 - Had no problems getting referrals if needed
- Nearly 60.0% of respondents met the definition for receiving care in a medical home. This is above the Alabama estimate for care received in a medical home from the National Survey of Children with Special Health Care Needs (50.7%).
 - National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [05/20/2015] from www.childhealthdata.org.
- The two criterion with lowest success rates were "Had no problems getting referrals if needed" and "Usually or always" felt like a partner with provider".

Receipt of care within a medical home

	Number reporting "Yes"	Percent reporting "Yes"
Met definition for having a medical home	391	59.3
Have personal doctor or nurse	631	90.1
Usually or always felt like a partner with provider	577	84.7
Believed provider was usually or always sensitive to family values and customs	585	88.2
Got an interpreter if needed one	680	97.2
Were very or somewhat satisfied with communication among providers	640	91.2
Had no problems getting referrals if needed	609	84.0

D. Transition to Adulthood

- Respondents were asked a series of questions that mirror those from the National Survey of Children with Special Health Care Needs in order to determine the extent to which these Alabama youth with special health care needs received support for the transition to adulthood. The definition of transition included work, school, health care, and community life.
- Analyses were limited to youth ages 12-25 years and youth ages 16-25 years.
- In order to meet the definition for receiving necessary supports for transition to adulthood, respondents must have met all of the following criteria:
 - Provider has discussed needs as youth becomes an adult
 - Provider "usually" or "always" encourages youth to take responsibility for health needs
 - Someone has encouraged planning for getting and keeping health insurance into adulthood
 - Someone has encouraged finding an adult physician
- Approximately 4.0% of respondents with youth ages 12-25 years and nearly 6.0% of respondents with youth ages 16-25 years met the criteria for receiving necessary supports for transition to adulthood. This was substantially lower than the Alabama estimate for transition supports from the National Survey of Children with Special Health Care Needs (34.8%).
 - National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [05/20/2015] from www.childhealthdata.org.
- The two criterion with the lowest success rates were "someone has encouraged planning for getting and keeping health insurance into adulthood" and "someone has encouraged finding an adult physician".
- Respondents were also presented with a list of future plans and activities and asked to indicate whether anyone (doctor, nurse, care coordinator) had encouraged them you to begin making plans with their youth for any of these activities. Analyses are presented for respondents with youth ages 16-25 years.
- Overall, reports of having these discussions were low. The most frequently-reported topics were completing high school and living with parents. Less than one-third of respondents reported having discussions about any of the other future plans and activities.

Receipt of supports for transition to adulthood

	Ages 12-25 years		Ages 16-25 years	
	Number reporting "Yes"	Percent reporting "Yes"	Number reporting "Yes"	Percent reporting "Yes"
Met definition for having supports for transition to adulthood	12	4.2	8	5.7
Provider has discussed needs as youth becomes an adult	151	53.4	93	65.0
Provider usually or always encourages youth to take responsibility for health needs	137	49.5	71	52.2
Someone has encouraged planning for getting and keeping health insurance into adulthood	35	11.9	23	15.5
Someone has encouraged finding an adult physician	45	15.2	37	25.0

Future plans and activities reported as having been discussed with a provider, respondents with youth ages 16-25 years, n=158

Future Plan Activities	Number reporting "Yes"	Percent reporting "Yes"
School activities		
Completing high school/GED	67	45.3
Completing technical/vocational school	15	10.1
Completing college	22	14.9
Health activities		
Getting and keeping health insurance	23	15.5
Finding an adult doctor	37	25.0
Recreation and exercise	40	27.0
Work/daily activities		
Day Program	21	14.2
Volunteering	10	6.8
Working for pay	44	29.7
Community activities		
Learning to drive	30	20.3
Registering to vote	18	12.2
Social relationships (friends, romantic)	45	30.4
Living arrangements		
Living independently (alone or with spouse or roommate)	21	14.2
Living with parents	60	40.5
Living in group home	4	2.7

E. Health Insurance and Health Policy Landscape

- Respondents were asked about the types of health insurance their child or youth had currently (if any) and whether there had been any time over the previous 12 months during which the child or youth did not have health insurance.
- Most respondents reported that their child or youth was currently covered by insurance – about 3.0% were uninsured. Approximately 8.0% reported there had been at least some time during the previous 12 months during which their child or youth was uninsured.
- Over three-fourths of respondents (76.9%) indicated their child or youth currently had public insurance, while more than one-third (36.6%) reported private insurance.
- Respondents were asked about their knowledge of upcoming changes to the Alabama Medicaid system and their perception of how these changes might impact their family.
 - Most survey respondents knew little about the changes, including those who said they currently received Medicaid (86.6% of the overall sample and 84.3% of Medicaid recipients reported they knew “nothing” about these changes).
- Respondents were also asked about their knowledge of the Affordable Care Act (ACA) and how this law might impact their family.
 - More than half (66.1%) reported they knew “only a little” or “nothing” about the ACA.
 - Most respondents (62.3%) indicated they did not know or were not sure how the ACA might impact their family. Among those who indicated a direction of impact, about one-fifth (21.2%) indicated their family would be worse off as a result of the ACA.

Health insurance coverage for children and youth with special health care needs

	Number reporting “Yes”	Percent reporting “Yes”
No insurance	20	3.2
Any time without insurance in previous 12 months	56	8.1
Had Public Insurance at time of survey (Medicaid, All Kids, Medicare)	516	76.9
Had Private Insurance at time of survey (Blue Cross, United Health, Viva, Tricare)	254	36.6

How much do you know about the new Medicaid Regional Care Organizations?

	Full Sample		Medicaid Recipients Only	
	N	%	N	%
A lot	25	3.5	17	3.7
Some	70	9.8	54	11.9
Only a little	93	13.1	58	12.8
Nothing	523	73.6	324	71.5

How much do you know about the health reform law known as the Affordable Care Act, sometimes called “Obamacare”?

	N	%
A lot	54	7.5
Some	189	26.3
Only a little	270	37.6
Nothing	205	28.5

Perception of family impact from the Affordable Care Act

I believe my family will be...	N	%
Unaffected by the Affordable Care Act	73	10.2
Better off as a result of the Affordable Care Act	45	6.3
Worse off as a result of the Affordable Care Act	152	12.2
Don't Know / Not Sure	447	62.3

F. Emergency Preparedness

- Respondents were asked a series of questions about their level of preparedness for emergencies and disasters.
- Ideally, a definition for “emergency” should have been provided. Given the absence of a definition, evaluators were unsure whether respondents considered only medical emergencies instead of natural disasters or other emergency situations. This supposition is supported by information obtained through focus groups with families and youth. More assessment is warranted in this area to determine family/youth understanding of emergency and disaster, as well as to elicit more detailed information about emergency plans and kits that are structured specifically to meet the child/youth’s unique health and medical needs.
 - Over two-thirds of all respondents (67.2%) indicated they had a plan in place to cover their child or youth’s needs in an emergency, and over half (52.0%) said they had a preparedness kit that would meet their child’s needs.
 - More than one-third (38.2%) of all respondents reported that their child or youth would require assistance beyond what they could provide if they had to evacuate to a mass care shelter.
 - Less than one-third (31.8%) of all respondents said that they had an up-to-date copy of their child or youth’s medical records (digital or paper) on-hand if they had to evacuate to another city or state during a disaster.
 - There were no statistically significant differences in responses between families of children and youth by functional level on emergency preparedness items except for the item related to assistance during an evacuation. Respondents with children and youth who had functional scores indicating less independence were statistically significantly more likely to report that their child or youth would require assistance beyond what they could provide if they had to evacuate to a mass care shelter compared with respondents whose children had functional scores indicating more independence.
- Respondents were also asked about their perception of whether their child/youth’s school could take care of his or her special health care needs in an emergency if he/she had to shelter there for an extended period of time. This was of special interest since during the winter before the survey a sudden ice storm in much of the northern portions of the state forced students to stay overnight for one to two nights due to impassible roadways. This situation created unique challenges for schools and emergency responders to provide accommodations and meet needs.
 - There was a statistically significant difference in responses between families by functional level. Respondents with children and youth who had functional scores indicating less independence were less likely to report they were “very sure” the school could take care of their child’s needs and more likely to report they “did not know” or “did not think” the school could meet their child’s needs compared with respondents whose children had functional scores indicating more independence.

Emergency preparedness among respondents with children and youth with special health care needs

	All N (%)	More independent functional level N (%)		
		Yes	No	p-value ¹
Has a plan in place to cover child(ren)/youth's needs in an emergency	432 (67.2)	100 (68.0)	109 (63.4)	0.383
Has a preparedness kit that will meet child(ren)/youth's special health care needs in an emergency	357 (52.0)	79 (50.0)	89 (48.6)	0.801
Child(ren)/youth would require assistance beyond what respondent is able to provide if had to evacuate to a mass care shelter	226 (38.2)	36 (26.7)	91 (56.5)	0.000
Has an up-to-date copy of child(ren)/youth's medical records (digital or paper) on-hand if had to evacuate to another city or state during a disaster	215 (31.8)	48 (29.8)	55 (31.4)	0.748

¹ Chi-square analyses

Family assessment of child/youth school's ability to take care of his/her special health care needs in an emergency if he/she had to shelter there for an extended period of time

	All N (%)	More independent functional level N(%)		p-value ¹
		Yes	No	
Very sure the school could take care of the needs – no concerns	247 (36.1)	72 (46.5)	56 (30.3)	0.002
Somewhat sure the school could take care of the needs – some concerns	165 (24.1)	46 (29.5)	47 (25.4)	
Only a little sure the school could take care of the needs – major concerns	66 (9.6)	11 (7.0)	19 (10.3)	
Do not think the school could take care of the needs at all	78 (11.4)	12 (9.6)	33 (17.8)	
Do not know	129 (18.8)	15 (9.6)	30 (16.2)	

¹ Chi-square analyses; $X=16.60$

G. Social Media Usage

- Respondents were asked about their social media usage, including frequency of use, types of platforms used, and the reasons or kinds of activities they engaged in through social media.
- Facebook was the most frequently-used social media platform, with 49.4% of respondents indicating they used it "at least once a day or more" and an additional 17.0% reporting they used it "a few times a week." Other platforms are presented in order of frequency of use: Google Plus, Pinterest, Instagram, Twitter, Blogs, Snapchat, and LinkedIn.
- The most commonly-reported reasons or kinds of activities engaged in through social media were fairly general as opposed to activities specific to the child or youth's special health care needs. The top-five reported reasons/activities were:
 - "Stay in touch with friends and family"
 - "Read the news"
 - "View photos, pages, and videos just for fun"
 - "Find out about local events"
 - "Learn more about my child/youth's health conditions or disability"

Reasons or kinds of activities engaged in through social media, ordered by frequency of reporting

	N	%
Stay in touch with friends and family	499	74.0
Read the news	367	54.4
View photos, pages, and videos just for fun	365	54.1
Find out about local events	282	41.8
Learn more about my child/youth's health conditions or disability	271	40.2
Share my thoughts and feelings	247	36.6
Learn about and promote causes or groups that are important to me	191	28.3
Learn about how I can be healthy (like how to exercise, what to eat)	171	25.4
Buy and sell things	166	24.6
Meet other parents of children/youth who have conditions like my children/youth	152	22.5
Learn about how my child/youth can be healthy (like how to exercise, what to eat)	130	19.3
Use online support groups or pages to help me deal with problems in my life	110	16.3
Communicate with my child/youth's health care providers	108	16.0
Meet new people in general	101	15.0
Learn about and make connections for jobs	95	14.1
Learn about college or other education programs after high school for my child/youth	93	13.8
Advertise business or for work-related purposes	3	<1.0
Communicate with school/keep up with school events	2	<1.0

H. Information Needs

- Respondents were provided a list of topics and asked to indicate the types of information for which they would like to have more information.
- The top-five reported information needs were:
 - My child(ren)/youth's condition or disability
 - Recreational activities (activities your child/youth does for fun)
 - Developing an emergency preparedness plan for my family and Healthy behaviors (exercise, eating well, etc.) - (tie)
 - Creating an emergency preparedness kit that will meet my child(ren)/youth's special health care needs and Meeting other parents of children/youth with disabilities/health conditions - (tie)

Information needs reported by families of children and youth with special health care needs, ordered by most frequently-reported

	N	%
My child(ren)/youth's condition or disability	229	41.7
Recreational activities (activities your child/youth does for fun)	201	36.6
Developing an emergency preparedness plan for my family	179	32.6
Healthy behaviors (exercise, eating well, etc.)	179	32.6
Creating an emergency preparedness kit that will meet my child(ren)/youth's special health care needs	169	30.8
Meeting other parents of children/youth with disabilities/health conditions	169	30.8
Education after high school (college, vocational/trade programs, technical school)	163	29.7
Successful people living with my child/youth's condition/disability	150	27.3
Finding an adult health provider when child(ren)/youth reaches adulthood	147	26.8
Jobs/careers for my youth	146	26.6
How my child(ren)/youth can take care of medical needs independently	128	23.3
Ways for me to partner with my child(ren)/youth's doctor to make good health decisions	103	18.8
Opportunities for me to get involved in advisory groups, committees, and policy leadership roles	102	18.6
Ways for my child(ren)/youth to talk to a doctor about health needs	88	16.0
How to use social media	38	6.9
Other: insurance; respite care; out-of-school care; planning for care when parents no longer able to provide; day program/sheltered workshop;	22	4.0

V. Strengths, Challenges, and Lessons Learned

The survey marketing methods used by CRS appear to have been successful based on the number of responses; however, a response rate could not be calculated. The sample size and survey demographics suggest that respondents were representative of the population of families with CYSHCN across Alabama counties and rural versus urban areas. Responses provide extensive and powerful information to guide the identification of needs and potential solutions. However, readers are cautioned to consider these findings in addition to those from other methods and data from the 2015 needs assessment to best triangulate issues and needs. Future research endeavors should consider opportunities to increase the number of survey responses and to increase diversity of children and youth across functional levels and disability/special health care need type.

CRS Provider Survey

Report of Survey of Primary Care Providers for Children and Youth with Special Health Care Needs
Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
A portion of the 2015 Title V Maternal and Child Health Needs Assessment
Completed by UAB School of Public Health, Department of Health Care Organization and Policy



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I. Introduction

As a part of the 2015 Title V Maternal and Child Health (MCH) Needs Assessment, the Alabama Department of Rehabilitation Services, Children's Rehabilitation Service (CRS) entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB) to develop, analyze, and report on a survey of primary care providers for Alabama children and youth with special health care needs (CYSHCN). Survey design was a partnership between UAB and CRS. CRS was responsible for all marketing and recruitment efforts related to the survey. UAB performed all analyses and developed final reports.

NOTE: Questions related specifically to other MCH population groups (women, women of child-bearing age, children, and their families) were not a part of the CRS Family Survey. Perspectives of these groups were captured by the Title V MCH Program, located in the Bureau of Family Health Services in the Alabama Department of Public Health. A separate report is available related to those groups. The final Alabama 2015 MCH Needs Assessment Report includes perspectives from all MCH populations in the state, including CYSHCN and their families.

II. Methods

A. Survey Design and Format

UAB and CRS developed a survey based on previous instruments, the Medical Home Index – Short Version and the Medical Home Health Care Transition Index (Center for Medical Home Improvement, 2006), best practices in survey design, the new guidance documents for the MCH Block Grant/Needs Assessment, and areas of interest identified by an internal needs assessment leadership team at CRS. The survey was available online and in hard copy formats in English. UAB developed the survey in the survey design and collection software Qualtrics, and the URL was linked to a user-friendly domain name purchased through a third-party vendor. The link supported easier marketing and dissemination (www.CRSprovidersurvey.com). Hard copy survey responses were hand entered by staff in the UAB Evaluation and Assessment Unit, with at least 10% re-check by an alternate staff member to ensure accuracy of data entry. Survey responses were anonymous, and the survey was available for completion in the summer and early fall of 2014.

B. Marketing and Recruitment

CRS was responsible for all marketing and recruitment efforts for the survey. Strategies included outreach to primary care practices by CRS local office staff members, social media marketing campaigns, and sharing of the survey link via partner agency/organization communication methods.

C. Analyses

All analyses were conducted by UAB using Stata statistical software.

III. Demographics of the Sample

- There were 30 responses in total, but only 15 were primary care providers. Some respondents identified themselves as other health-related professionals and community-based service providers (Part C early intervention specialist, dentist, physical therapist, durable medical equipment provider, specialty care physician, etc.). These non-primary care provider responses were removed from analyses.
- The final sample included primary care providers located in 10 of Alabama's 67 counties. Of those counties, five are designated rural and five are designated urban.
- Provider respondents primarily identified themselves as pediatricians (over 93.0%) or adolescent medicine specialists; Nearly all reported they worked in group practices (93.3%).
- Nearly three-fourths of respondents (n=11) had practiced medicine for 11 years or more.
- Nearly 80.0% (n=11) of providers reported their practice was comprised of 1-25% CYSHCN and nearly 90.0% (n=13) were open to serving new CYSHCN patients.

Characteristics of primary care provider respondents

Characteristic	N	%
Specialty area		
Pediatrics (including Developmental/Behavioral pediatrics)	14	93.3
Adolescent Medicine	1	6.7
Years practicing medicine		
1-5 years	1	6.7
6-10 years	3	20.0
11 or more years	11	73.3
Type of practice		
Individual	1	6.7
Group	14	93.3
Practice acceptance of new patients		
Not accepting any new patients	0	0
Yes to all, including CYSHCN	11	73.3
Yes to selected patients	4	26.7
Practice serves CYSHCN		
No	0	0
Yes	15	100
Percentage of practice that is CYSHCN		
1-25%	11	78.6
26-50%	2	14.3
51-75%	0	0
More than 75%	1	7.1
Practice open to new CYSHCN		
Yes	13	86.7
Limited basis (age, insurance status, percentage of practice)	2	13.3

IV. Findings

A. Medical Home

- Questions were modified from the Medical Home Index-Short Version (Center for Medical Home Improvement, 2006). The survey covered eight of 10 indicators, which were derived from the original, full version (25 items) of the Medical Home Index (MHI).
 - The MHI is a nationally validated self-assessment tool designed to quantify the “medical homeness” of a primary care practice.
- The MHI-Short Version scores a practice on a continuum of care across three levels:
 - Level 1 is good, responsive pediatric primary care.
 - Level 2 is pro-active pediatric primary care (in addition to Level 1)
 - Level 3 illustrates pediatric primary care at the most comprehensive levels (it is in addition to Levels 1 and 2).
- Scores are calculated for each indicator based on a 1-5 scale,
 - 1 = Level 1
 - 2 = Level 2 – partial
 - 3 = Level 2 – complete
 - 4 = Level 3 – partial
 - 5 = Level 3 – complete
- Statements that described the practice at each level of “medical homeness” were provided in accordance with the tool guidelines. Respondents selected all that applied under each indicator. Answers were coded to the appropriate level and the overall score and scores by indicator were calculated based on the highest level completed.

- **The mean overall level of medical home for this sample of 15 primary care providers was 2.90, or approximately a Level 2 – complete.**
 - Lowest mean scores – indicating lowest levels of performance – were noted for the indicators “Supporting the Transition to Adulthood” (2.40) and “Family Feedback” (2.33)
- Considering selected items related to medical home:
 - Though 80.0% of providers (12 of 15) reported having materials available for non-English speakers, fewer than half (46.7%, 7 of 15) indicated their materials were appropriate for people with lower literacy or developmental levels.
 - Though 40.0% of practices (6 of 15) indicated they had a designated care coordinator, few (20.0%, 3 of 15) reported that their care coordination includes written care plans with ongoing monitoring. Fewer still, 13.3% of practices (2 of 15) noted that their practice (together with the family and child/youth) creates a written plan of care that is then monitored at every visit to assess needs and plans for care.

Level of medical home, overall and by indicator, based on modified Medical Home Index – Short Version; n = 15 primary care providers

Medical Home Indicator	Level 1 Responsive N (%)	Level 2 Proactive N (%)	Level 3 Comprehensive N (%)	Mean (1-5)
Identification of Children in the Practice with Special Health Care Needs	0 (0)	5 (38.5)	8 (61.5)	3.77
Care Coordination/ Role Definition	1 (7.1)	6 (42.8)	7 (50.0)	3.14
Cultural Competence	1 (7.1)	7 (50.0)	6 (42.8)	3.14
Care Continuity	1 (7.1)	7 (50.0)	6 (42.9)	3.07
Quality Standards	3 (21.4)	4 (28.6)	7 (50.0)	2.86
Assessment of Needs/Plans of Care	1 (7.1)	10 (71.4)	3 (21.4)	2.50
Supporting the Transition to Adulthood	2 (13.3)	10 (66.7)	3 (20.0)	2.40
Family Feedback	5 (33.3)	10 (66.7)	0 (0)	2.33
Overall				2.90

Selected questions and responses related to medical home

	N (%)
How does your practice consider the cultural background and beliefs of your patients as you deliver care?	
Materials are available for non-English speakers	12 (80.0)
Materials are appropriate for people with lower literacy or developmental levels	7 (46.7)
How is care coordinated for CYSHCN in your practice?	
My practice has a designated care coordinator	6 (40.0)
Our care coordination includes written care plans with ongoing monitoring	3 (20.0)
How does your practice assess needs and plan for the care of CYSHCN in your practice?	
Together with the family and child/youth, we create a written plan of care that is monitored at every visit	2 (13.3)

B. Transition to Adult Health Care

- Questions were modified from the Medical Home Health Care Transition Index (Got Transition and the Center for Medical Home Improvement, 2011). The survey covered all six indicators.
 - The Medical Home Health Care Transition Index was modeled after the Medical Home Index. It is a measure of health care transition support in pediatric practices and is designed to align with the recommendations of the AAP/AAFP/ACP joint clinical report and algorithm on health care transition (Pediatrics, 2011).
- The Medical Home Health Care Transition Index scores a practice on a continuum of care across four levels:
 - Level 1 is Basic.
 - Level 2 is Responsive (in addition to Level 1).
 - Level 3 is Proactive (it is in addition to Levels 1 and 2).
 - Level 4 is Comprehensive (it is in addition to Levels 1-3).
- Scores are calculated for each indicator based on a 1-8 scale, including partial and complete within each level,
 - 1 = Level 1 – partial
 - 2 = Level 1 - complete
 - 3 = Level 2 – partial
 - 4 = Level 2 – complete
 - 5 = Level 3 – partial
 - 6 = Level 3 – complete
 - 7 = Level 4 – partial
 - 8 = Level 4 – complete
- Statements that describe the practice at each level of transition support were provided in accordance with the tool guidelines. Respondents selected all that applied under each domain. Answers were coded to the appropriate level, and the overall score and scores by domain were calculated based on the highest level completed.
- **The mean overall level of transition support for this sample of 15 primary care providers was 3.75, or between a Level 2 – partial and Level 2 - complete.**
 - Lowest mean scores – indicating lowest levels of performance – were noted for the domains “Transition preparation” (3.71) and “Identification of transitioning youth” (3.08)
- Considering selected items related to transition:
 - The type of support provided for transition to adulthood varied, but few practices (26.7%, 4 of 15) reported working with youth and their families to develop a written transition plan that was available to the families and all involved providers.
 - Few practices had a uniform transition and transfer of care policy, written (20.0%, 3 of 15) or not (13.3%, 2 of 15).

- o Though 60.0% of providers (9 of 15) reported that youth begin a process of knowing their own health and wellness, risk behaviors, allergies, personal and family health history, and insurance coverage by at least age 14, only about one-fourth (26.7%, 4 of 15) indicated that youth were seen without their family members for portions of encounters after age 14. Fewer still (13.3%, 2 of 15) responded that by age 14, a transition plan was developed with the family/youth/provider, placed in the medical record, and updated at designated intervals.

Level of transition support, overall and by indicator, based on modified Medical Home Health Care Transition Index; n = 15 primary care providers

Transition Domain	Level 1 Basic N (%)	Level 2 Responsive N (%)	Level 3 Proactive N (%)	Level 4 Comprehensive N (%)	Mean (1-8)
Transfer of care (when appropriate)	2 (15.4)	7 (53.8)	2 (15.4)	2 (15.4)	4.08
Office health care transition policy	2 (14.3)	7 (50.0)	2 (14.3)	3 (21.4)	4.07
Transition Planning	2 (14.3)	8 (57.1)	1 (7.1)	3 (21.4)	3.79
Staff and provider knowledge and skills	3 (21.4)	9 (64.3)	0 (0)	2 (14.3)	3.79
Transition Preparation	2 (14.3)	8 (57.1)	3 (21.4)	1 (7.1)	3.71
Identification of transitioning youth	8 (61.5)	3 (23.1)	1 (7.7)	1 (7.7)	3.08
Overall					3.75

Selected questions and responses related to transition

	N (%)
How does your practice support transition to adulthood for youth with special health care needs specifically?	
We provide guidance on health and wellness	9 (60.0)
We provide guidance on education and vocational planning	6 (40.0)
We provide guidance on community-supports & recreation	6 (40.0)
We provide guidance on guardianship and legal & financial issues	3 (20.0)
We work with youth and their families to develop a written transition plan that is available to the families and all involved providers	4 (26.7)
Tell us about your office's health care transition policy.	
Our office has a uniform, but not necessarily written, transition and transfer of care policy that is agreed upon by all providers and is made clear to staff	2 (13.3)
Our office has a written transition and transfer of care policy	3 (20.0)
Transition preparation and planning for youth with special health care needs	
Youth are seen without their family members for portions of encounters after age 14	4 (26.7)
By at least age 14, all youth begin a process of knowing their own health and wellness, risk behaviors, allergies, personal and family health history, insurance coverage	9 (60.0)
By age 14, family/youth/providers start a transition plan; the transition plan is in the medical record and is updated at designated intervals throughout the transition period	2 (13.3)

V. Strengths, Challenges, and Lessons Learned

This survey represents a modification of two national survey instruments used to measure medical home and support for transition for CYSHCN. Though a direct comparison with these tools cannot be made due to modifications necessary for a project of this type, the indicators and domains were the same, as were the response choices. This allows for approximations and general comparisons with national data. The sample size for the provider survey was too small for any advanced statistical analyses. Results are based on 15 respondents, with many responses at five or fewer. These data should be considered as the perceptions of a small group of providers, without drawing inferences or conclusions based on responses. Findings presented from the provider survey are most-appropriately considered trends that contribute to the identification of needs and potential solutions. Results are not generalizable to Alabama's primary care providers for CYSHCN. Readers are cautioned to consider these findings in addition to those from other methods and data from the 2015 needs assessment to best triangulate issues and needs. Future endeavors should consider opportunities to increase the number of survey responses.

CRS Youth Survey

Report of Survey of Youth with Special Health Care Needs
Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
A portion of the 2015 Title V Maternal and Child Health Needs Assessment
Completed by UAB School of Public Health, Department of Health Care Organization and Policy



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I. Introduction

As a part of the 2015 Title V Maternal and Child Health (MCH) Needs Assessment, the Alabama Department of Rehabilitation Services, Children's Rehabilitation Service (CRS) entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB) to develop, analyze, and report on a survey of Alabama youth with special health care needs (YSHCN). Survey design was a partnership between UAB and CRS. CRS was responsible for all marketing and recruitment efforts related to the survey. UAB performed all analyses and developed final reports.

II. Methods

A. Survey Design and Format

UAB and CRS developed a survey based on previous instruments, best practices in survey design, the new guidance documents for the MCH Block Grant/Needs Assessment, and areas of interest identified by an internal needs assessment leadership team at CRS. The survey was available online and in hard copy format in English and Spanish. UAB developed the survey in the survey design and collection software Qualtrics, and the URL was linked to a user-friendly domain name purchased through a third-party vendor. The link supported easier marketing and dissemination (www.CRSfamilysurvey.com). Hard copy survey responses were hand entered by staff in the UAB Evaluation and Assessment Unit, with at least 10% recheck by an alternate staff member to ensure accuracy of data entry. Survey responses were anonymous, and the survey was available for completion in the summer and early fall of 2014.

B. Marketing and Recruitment

CRS was responsible for all marketing and recruitment efforts for the survey. Strategies included hard copies made available in CRS clinics, postcards with the survey link provided in local CRS offices, hard copies and postcards provided at focus groups (also conducted as a part of the overall needs assessment methods), social media marketing campaigns, and sharing of the survey link via partner agency/organization communication methods.

C. Analyses

All analyses were conducted by UAB using Stata statistical software.

III. Demographics of the Sample

- N = 248
- At least 1 response from 53 of Alabama's 67 counties
- The majority respondents completed the survey in hard copy format (73.7%) and in English (96.6%).
- Rural versus Urban designations were assigned based on two methods:
 1. Whether the county lies within a metropolitan statistical area (MSA) (U.S. Office of Management and Budget definition), and
 2. Alabama Rural Health Association definition ("What is Rural?")
- Both methods are discussed at the following: www.arhaonline.org/about-us/what-is-rural/
- Though the MSA definition is recommended by the U.S. Office of Management and Budget, the alternate classification was also incorporated in analyses as it has been used by CRS in previous needs assessment reports. These methods differ in that more Alabama counties are designated "urban" according to MSA inclusion as compared to the Alabama Rural Health Association definition.
- Using the MSA designation, the majority of respondents were from urban counties (65.3%). Using the alternative classification, the percentages of rural versus urban residencies were similar (46.5% and 53.5%, respectively).

Survey format and language

	N	%
Survey Format		
Online	77	31.0
Hard Copy	171	68.9
Survey Language		
English	243	98.0
Spanish	5	2.0

Participants by county type, based on MSA definition

County Type	N	%
Rural – not in MSA	74	34.7
Urban – in MSA	139	65.3

Participants by county type, based on “What is Rural?” definition

County Type	N	%
Rural	99	46.5
Urban	114	53.5

- Roughly two-thirds of the sample were ages 12-18 years, with 36.4% reporting their age as 19 years or older.
- Most respondents (60.7%) had less than a high school education or were still in middle or high school.
- Approximately two-thirds of respondents (66.5%) self-identified as “white” and nearly 37.0% self-reported as “black.”
- Most youth reported that they had health insurance coverage– 6.4% were uninsured. Less than 5.0% (4.4%) did not know about their health insurance status or type.
- About two-thirds of respondents (63.2%) indicated they had public insurance, while over one-third (35.3%) reported private insurance.
- The most common health conditions reported were (data not shown):
 - learning disability
 - respiratory problems (asthma, cystic fibrosis)
 - orthopedic conditions
 - attention deficit disorder
 - cerebral palsy
 - epilepsy
 - deafness/hearing impairment
 - speech/language problems/disorder
 - autism spectrum disorder
- Youth were asked for their perception of how often their health condition affected their ability to do things. Responses varied, with “sometimes” being selected most frequently.
- Nearly 60.0% of youth completed the survey independently without assistance from anyone. Among those who reported receiving some assistance (29.0%), reading questions to the youth or writing down the youth’s responses were the most common types of assistance. Slightly more than 11.0% of responses about youth were entirely completed by someone else without the youth’s input.

Respondent characteristics, youth with special health care needs

Respondent Characteristic	N	%
Age		
15 years and younger	68	31.8
16-18 years	68	31.8
19-24 years and older	78	36.4
Highest level of education		
Less than high school/ still in middle or high school	125	60.7
High school diploma or GED	45	21.8
Some college (did not graduate)/ still in college	17	8.2
Education beyond high school (vocational training, trade school, Associate's degree, Bachelor's degree or higher)	19	9.2
Race/ethnicity		
Hispanic	10	5.2
Asian	2	1.0
Black	79	36.9
White	129	66.5
Other/Multiple	8	3.8
Insurance type		
Public (Medicaid, All-Kids, Medicare)	129	63.2
Private (Blue Cross/Blue Shield, United Health Care, Viva, Tricare)	72	35.3
No insurance	13	6.4
Do not know	9	4.4
How often health condition affects youth's ability to do things		
Always	37	18.9
Usually	37	18.9
Sometimes	73	37.2
Rarely	26	13.3
Never	23	11.7
Assistance from someone else to complete survey		
No assistance (youth completed independently)	115	59.6
Some assistance	56	29.0
<i>Someone read the questions to me</i>	20	10.4
<i>Someone translated the questions into my language</i>	7	3.6
<i>I said the answer and someone wrote down what I said</i>	17	8.8
<i>Other/Combination</i>	12	6.2
Total assistance (someone else completed the survey based on what they thought – the youth was not a part of answering the survey at all)	22	11.4

- Functional levels for YSHCN were determined based on a series of questions modified from the standardized assessment, Functional Independence Measure (FIM). Since this tool is intended for clinicians, items and language of the measurement scale were modified to make it easier for respondents to understand and use. The purpose of the FIM is to provide a uniform system of measurement for disability based on the International Classification of Impairment, Disabilities and Handicaps. This tool indicates the amount of assistance required for an individual to carry out activities of daily living.

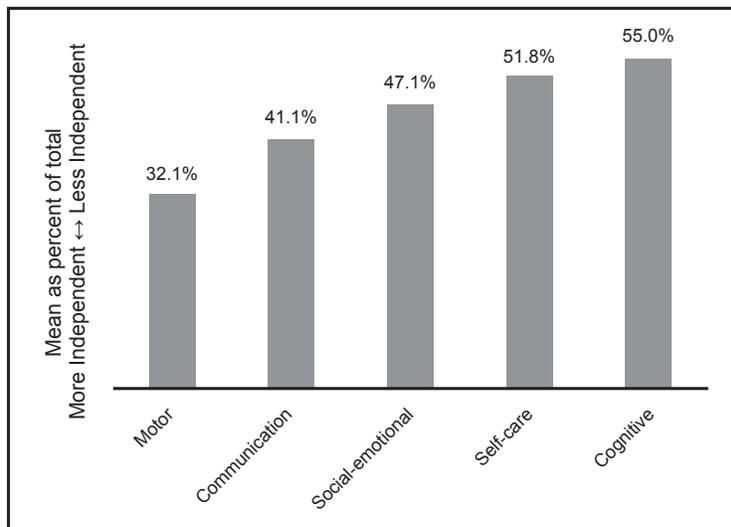
- Functional levels were calculated for the full sample of youth using the modified instrument. A total of 13 daily living skills were presented, with 11 applied to all ages and two additional skills reserved for youth ages 16 and older.
- Respondents considered each item and selected a score that matched the level of assistance they needed based on the following scale:
 - 1 = Can do by themselves with no help
 - 2 = Can do by themselves, but needs a little more time or to use equipment (braces, wheelchair, walker, bath seat)
 - 3 = Can do by themselves, but needs someone to watch for safety or to give cues
 - 4 = Mostly can do, but needs just a little help from someone
 - 5 = Can do some, but needs a good bit of help from someone
 - 6 = Can do a little, but needs a lot of help from someone
 - 7 = Can't do at all - someone else must do it for them
- Daily living skills were grouped into the following daily living skill areas:
 - Self-care skills:
 - Bathing/Dressing, Feeding self/Drinking, Take care of toileting, and Using equipment or braces
 - Motor skills:
 - Moving his/her body from one place to another and Using hands and arms
 - Cognitive skills:
 - Learning and using new information and Focusing and keeping attention
 - Social-emotional skills:
 - Keeping control over emotions and behaviors and Interacting or connecting socially with others
 - Communication skills:
 - Using spoken language to communicate with others
- The 50th percentile score was calculated for overall functional levels to identify groups with more independence (mean scores below the 50th percentile) vs. those with less independence (mean scores above the 50th percentile) overall. This designation was incorporated into select analyses (see next section).
- Lower scores – by item, skill area group, or overall – indicated more independence. Mean scores were calculated for each item, skill area group, and overall. A percentage completion of the total possible score was calculated for each skill area group by dividing the mean for the area by the total points possible for the area and converting it to a percentage. The higher the percentage, the higher the score and the more assistance required to complete skills (less independence).
 - Youth had highest levels of independence with motor skills and lowest levels of independence with cognitive skills.

Functional Skill Levels (Scale 1 – 7, 1=independent; 7=dependent)	Range of Possible Scores	Mean
Functional Skills Bathing / Dressing Feeding self / Drinking Take care of toileting Moving his/her body from one place to another Using hands and arms Using equipment or braces Taking medicines ¹ Learning and using new information Managing money ¹ Focusing and keeping attention Keeping control over emotions and behaviors Interacting or connecting socially with others Using spoken language to communicate with others	1-7, each	2.00 1.56 1.82 1.62 1.45 1.98 2.43 2.38 2.88 2.38 2.24 2.05 1.84
Overall functional level (full sample) Self-care skills Motor skills Cognitive skills Social-emotional skills Communication skills	11-77 4-28 2-14 2-14 1-7	21.36 7.69 3.08 4.69 4.29 1.84

¹Included for youth ages 16 years and older only

	N	%
Functional level - overall (full sample) More independent (below 50 th percentile) Less independent (above 50 th percentile)	71 59	54.6 45.4

Functional independence levels by activity of daily living skills areas calculated by dividing mean score by total score possible for each area



IV. Findings

A. Social Activities

- Approximately one-third (33.7%) of youth reported spending “a lot” of time doing things with people outside their home while nearly half (47.2%) reported they sometimes did things with people outside their home.
- Respondents were provided a list of activities and asked to indicate how often they engaged in each one. Respondents selected one of the following responses:
 - “Very often (daily to weekly)”
 - “Somewhat often (monthly)”
 - “Not very often (a few times a year)”
 - “Never”
- The top-four most frequently reported social activities (lowest mean scores and more than half the sample reported engaging in “very often”) were:
 - Listen to music
 - Watch television
 - Use computer, tablet, smartphone (games, Internet, social media)
 - Text or message with friends
- These activities were similar to what might be expected of youth in general. All are sedentary activities and may also be solitary activities engaged in while at home.
- Youth who lived in urban areas (by either definition) participated in one more social activity on average as compared to youth who lived in rural areas.
- Youth who had functional scores indicating more independence reported participating in three more social activities on average as compared to youth who had functional scores indicating less independence.

Time spent doing things with other people outside the youth’s home

	Frequency			
	Essentially no time N (%)	Rarely N (%)	Sometimes N (%)	A lot N (%)
Time spent doing things with other people outside the home	12 (6.0)	26 (13.1)	94 (47.2)	67 (33.7)

Social activity participation of youth with special health care needs, sorted by frequency

Activity	Frequency				Mean
	(4) Never N (%)	(3) Not very often (a few times a year) N (%)	(2) Somewhat often (monthly) N (%)	(1) Very often (daily to weekly) N (%)	
Listen to music	6 (2.9)	4 (2.0)	21 (10.3)	173 (84.4)	1.23
Watch television	2 (<1.0)	7 (3.4)	33 (16.0)	164 (79.6)	1.26
Computer, tablet, smartphone (games, Internet, social media)	12 (5.9)	9 (4.4)	24 (11.8)	159 (77.9)	1.38
Text or message with friends	36 (17.8)	9 (4.5)	30 (14.8)	127 (62.9)	1.77
Visit with friends	22 (10.8)	25 (12.3)	64 (31.5)	92 (45.3)	1.89
Shopping	11 (5.4)	30 (14.8)	89 (43.8)	73 (36.0)	1.90
Church activities	27 (13.3)	41 (20.2)	45 (22.2)	90 (44.3)	2.02
Movies, concerts	10 (5.0)	48 (23.9)	79 (39.3)	64 (31.8)	2.02
Read books or magazines	30 (14.8)	30 (14.8)	65 (32.0)	78 (38.4)	2.06
Hobbies (collecting things, painting, drawing)	32 (16.6)	40 (20.0)	53 (26.5)	75 (37.5)	2.14
Outdoor activities (biking, fishing)	34 (16.7)	49 (24.0)	62 (30.4)	59 (28.9)	2.28
Game systems (Wii, X-box, PlayStation)	55 (27.9)	32 (16.2)	44 (22.3)	66 (33.5)	2.39
Play sports	74 (37.4)	38 (19.2)	32 (16.2)	54 (27.3)	2.67
Watch sports in person	70 (35.2)	49 (24.6)	37 (18.6)	43 (21.6)	2.74
Volunteer activities	66 (33.0)	53 (26.5)	46 (23.0)	35 (17.5)	2.75
School clubs or groups (band, Scouts)	103 (52.3)	27 (13.7)	32 (16.2)	35 (17.8)	3.00
Work at a job	124 (62.0)	24 (12.0)	10 (5.0)	42 (21.0)	3.15
Play musical instrument	131 (64.8)	26 (12.9)	21 (10.4)	24 (11.9)	3.31
Camps (general of condition-specific)	116 (58.9)	58 (29.4)	13 (6.6)	10 (5.1)	3.42
Number of activities (range = 1-19)					10.9

Social activity participation among youth with special health care needs by rural/urban and functional level

	Rural vs Urban by MSA definition ¹		Rural vs Urban by previous definition ²		More independent functional level ³	
	Rural	Urban	Rural	Urban	Yes	No
Mean number of activities	10.2	11.3	10.3	11.4	12.6	9.6

¹ANOVA; $F=3.74$; $p=0.054$

²ANOVA; $F= 4.31$; $p=0.039$

³ANOVA; $F=20.34$; $p=0.000$

B. Social Media Usage

- Respondents were asked about their social media usage, including frequency of use, types of platforms used, and the reasons or kinds of activities they engaged in through social media.
- Facebook was the most frequently-used social media platform, with 48.0% of respondents indicating they used it “at least once a day or more” and an additional 16.3% reporting they used it “a few times a week.” Other platforms are presented in order of frequency of use: Instagram, Snapchat, Google Plus, Twitter, Pinterest, Blogs, LinkedIn, Other (Tumblr, Vine, YouTube).
- The most commonly-reported reasons or kinds of activities engaged in through social media were fairly general, recreational reasons as opposed to activities specific to the youth’s special health care need, education, meeting people, dealing with problems, or communicating with providers. The top-five reported reasons/activities were:
 - “Stay in touch with friends and family”
 - “View photos, pages, and videos just for fun”
 - “Read the news”
 - “Share my thoughts and feelings”
 - “Find out about local events”

Reasons or kinds of activities engaged in through social media, ordered by frequency of reporting

	N	%
Stay in touch with friends and family	135	81.8
View photos, pages, and videos just for fun	120	72.3
Read the news	83	50.3
Share my thoughts and feelings	69	41.8
Find out about local events	65	39.4
Learn about college or other education programs after high school	52	31.5
Buy and sell things	52	31.5
Learn about how I can be healthy (like how to exercise, what to eat)	44	26.7
Learn about and promote causes or groups that are important to me	37	22.4
Learn more about my health conditions or disability	37	22.4
Meet new people in general	34	20.6
Meet others who have conditions like mine	30	18.2
Learn about and make connections for jobs	23	13.9
Use online support groups or pages to help me deal with problems in my life	14	8.5
Communicate with my health care providers	13	7.9

C. Healthy Behaviors

i. Physical Activity

- More than a quarter of respondents (27.2%) reported that they had not been physically active or exercised at all over the previous week.
- Only 8.9% of youth met the CDC recommendations for physical activity (60 minutes per day each day) based on reported physical activity during the preceding week. The most commonly reported frequency of exercise for youth was no days. This finding is not entirely explained by functional skill levels of the youth based on reported assistance levels for daily living skills. It is also inconsistent with current support for adapted physical activity and recreational opportunities for individuals with disabilities.

Number of days in past week youth exercised, played a sport, or participated in a physical activity for at least 60 minutes that made him/her sweat and breathe hard	N	%
No days	55	27.2
1 day	25	12.4
2 days	27	13.4
3 days	27	13.4
4 days	19	9.4
5 days	23	11.4
6 days	8	4.0
7 days	18	8.9

ii. Nutrition

- Fruit and vegetable consumption was low overall; however, 64.0% of youth reported eating a fruit or vegetable at least 1 time per day over the preceding week.

Number of times ate fruit or vegetables in preceding week

Fruit and Vegetable Servings	Respondent	
	N	%
3 times per day or more	37	18.5
2 times per day	48	24.0
1 time per day	43	21.5
4 to 6 times during the past week	31	15.5
1 to 3 times during the past week	28	14.0
None	13	6.5

D. Transition to Adulthood

- Respondents were asked a series of questions that included transition-related items from the National Survey of Children with Special Health Care Needs in order to determine the extent to which these Alabama youth with special health care needs received support for the transition to adulthood. The definition of transition included work, school, health care, and community life.
- Though some concepts overlapped, transition as applied in the CRS Youth Survey could not be directly compared with transition as applied in the CRS Family Survey.
- Analyses were separated to the full sample (youth ages 12-25 years) and an older sub-sample of youth ages 16-25 years.
- In order to meet the definition for receiving necessary supports for transition to adulthood, respondents must have met all of the following criteria:
 - Provider has discussed needs as youth becomes an adult
 - Provider “usually” or “always” encourages youth to take responsibility for health needs
 - Provider “always” or “frequently” helped youth feel involved or included in health care decisions
 - Youth has opportunity to speak with provider privately during regular check-ups
- Approximately 18.0% of youth ages 12-25 years and 20.0% of youth ages 16-25 years met the definition for receiving necessary supports for transition to adulthood. This was lower than the Alabama estimate for transition supports from the National Survey of Children with Special Health Care Needs (34.8%).

- o National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [05/20/2015] from www.childhealthdata.org.
- The criteria with the lowest success rate was youth having opportunities to speak privately with their health provider.

Receipt of supports for transition to adulthood

	Ages 12-25 years		Ages 16-25 years	
	Number reporting "Yes"	Percent reporting "Yes"	Number reporting "Yes"	Percent reporting "Yes"
<i>Met definition for having supports for transition to adulthood</i>	31	17.9	22	20.4
Provider has discussed needs as youth becomes an adult	87	59.6	61	65.6
Provider usually or always encourages youth to take responsibility for health needs	98	58.7	68	60.2
Provider "always" or "frequently" helped youth feel involved or included in health care decisions	111	65.7	77	68.7
Youth has opportunity to speak with provider privately during regular check-ups	79	46.5	60	55.0

E. Future Plans

- Youth were presented with a list of future plans and activities and asked to indicate which plans and activities were part of their future plans. Analyses are presented for youth ages 16-25 years.
- About half of youth ages 16-25 years (52.2%) indicated they planned to complete college and over 61.0% reported they planned to work in a job for pay. Youth were planning more for friendships as opposed to marriage or romantic relationships (61.8% vs. 41.9%, respectively). Only one-third of youth planned to live independently (alone or with a spouse or roommate); more than half (59.6%) indicated they planned to live with their parents in the future. Less than 40.0% of youth were planning for transition to adulthood-related items, including "getting and keeping health insurance" (37.5%) and "finding an adult doctor" (33.8%).

Future plans and activities reported by youth ages 16-25 years, n=146*

Future Plan Activities	Number reporting "Yes"	Percent reporting "Yes"
School activities		
Completing high school/GED	52	38.2
Completing technical/vocational school	19	14.0
Completing college	71	52.2
Health activities		
Getting and keeping health insurance	51	37.5
Finding an adult doctor	46	33.8
Recreation and exercise	67	49.3
Work/daily activities		
Day Program	22	16.2
Volunteering	35	25.7
Working for pay	84	61.8
Community activities		
Learning to drive	41	30.1
Registering to vote	36	26.5
Getting married or in romantic relationships	57	41.9
Making friends	84	61.8
Living arrangements		
Living independently (alone or with spouse or roommate)	45	33.1
Living with parents	81	59.6
Living in group home	5	3.7

*136 youth ages 16-25 years answered this question

F. Mentorship and Support

- Youth were asked about their opportunities for support and mentorship through trusted adults and adult role models.
- Nearly all youth reported having at least one adult in his or her life that he/she could talk to about problems (98.4%) and to look up to as a role model (95.7%).

	N	%
Youth has at least one trusted adult he/she can talk to about serious problems or issues	180	98.4
Youth has at least one adult he/she can look up to as a role model	177	95.7

G. Information Needs

- Youth were provided a list of topics and asked to indicate the types of information for which they would like to have more information.
- The most frequently reported informational need was related to jobs/careers, with 50.0% of youth requesting information about this topic. Approximately one-third of youth indicated a need for information about education after high school (33.8%) or for information about their condition/disability (32.4%).

Information needs reported by youth with special health care needs, ordered by most frequently-reported

	N	%
Jobs/careers	71	50.0
Education after high school (college, vocational/trade programs, technical school)	48	33.8
My condition or disability	46	32.4
How I can be healthy (exercise, eat well, take care of myself)	41	28.9
Recreational activities	37	26.0
How to take care of my medical needs independently (schedule my appointments, take my medicine)	35	24.6
Successful people living with my condition/disability	34	23.9
Ways to meet other people who have disabilities/health conditions	33	23.2
How I can find an adult care doctor as I get older	30	21.1
Opportunities for me to get involved in advisory groups, committees, and leadership roles	25	17.6
Insurance, how to pay for my health care	23	16.2
How I can talk to the doctor about my health care needs	22	15.5
How to use social media	10	7.0

V. Strengths, Challenges, and Lessons Learned

The survey marketing methods used by CRS appear to have been successful; however, the overall sample size was small and a response rate could not be calculated. Results may not be generalizable to the Alabama YSHCN population. However, responses provided extensive and powerful information to guide the identification of needs and potential solutions. Readers are cautioned to consider these findings in addition to those from other methods and data from the 2015 needs assessment to best triangulate issues and needs. Future endeavors should consider opportunities to increase the number of survey responses and to increase diversity across functional levels and disability/special health care need type.

CRS Key Informant Interviews

Report of Key Informant Interviews regarding Children and Youth with Special Health Care Needs
Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
A portion of the 2015 Title V Maternal and Child Health Needs Assessment
Completed by UAB School of Public Health, Department of Health Care Organization and Policy



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I. Introduction

As a part of the 2015 Title V Maternal and Child Health Needs Assessment, Children's Rehabilitation Service (CRS) entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB) to plan, facilitate, analyze, and report on key informant interviews conducted with individuals with specialized knowledge of the needs of children and youth with special health care needs (CYSHCN) and their families, as well as the system of care and organizations that serves this population. CRS and UAB together developed a strategy to plan interviews that were representative of the service system for each of the 14 community-based offices located throughout the state. All Key Informant interviews were conducted by UAB faculty, staff, or graduate students.

II. Methods

A. Number, recruiting, and logistics

CRS State Office staff and its internal needs assessment leadership team identified potential key informants based on recommendations from local District Supervisors, Office Coordinators, and Parent Consultants. Individuals included representatives from local CRS offices, parents of CYSHCN, social workers, nurses, special educators, health care providers and representatives from other organizations providing care to CYSHCN and their families. Prior to key informant interviews, CRS local staff members contacted each potential interviewee to discuss the reason for the interview and to determine whether they were willing to participate. The final list of 20 potential key informants was provided to UAB by CRS. UAB conducted a total of 20 key informant interviews, all from the original list with the exception of one replacement name supplied by CRS due to the unavailability of one interviewee. All key informant interviews were conducted between September and October 2014. Key informants were not provided financial incentives for their participation.

B. Interview guide development

Building upon previous interview scripts provided by CRS and discussion of important topics of interest, UAB faculty developed interview guides for the key informant interviews. These interview scripts allowed for qualitative comments as well as quantitative ratings related to service availability and unmet needs in the area. The same interview script was utilized for each interview. Participants were provided with a copy of the interview script prior to the session to assist them in completing the interview.

C. Data analyses

Notes from key informant interviews were captured by hand and entered into a spreadsheet for data analysis. Quantitative analyses were performed as appropriate to the data (frequencies, means) and qualitative comments were coded by theme.

III. Findings

A. Ease of accessing health and health-related services:

- Key informant participants were provided a list of health and health-related services that might be needed and used by children and youth with special health care needs. Participants were instructed to rate how hard it was for children and youth with special health care needs who live in their area to obtain these services if they needed them. The rating scale was 1 to 10, "1" meant "it is very easy or no problem to get the service" and "10" meant "it is very hard or nearly impossible to get the service".
- Services are listed in order of hardest to easiest to access services based on mean scores. Ties were broken based on the percentage of respondents who rated the service in the 8-10 range, indicating these were among the hardest services for families to obtain for their children.

Table 1. Ease of accessing health and health-related services for children and youth with special health care needs, listed in order of hardest to easiest to access services

Service	Rating 1-3 N (%)	Rating 4-7 N (%)	Rating 8-10 N (%)	Mean Rating
1. Mental health / behavioral services	2 (10.0)	8 (40.0)	10 (50.0)	6.40
2. Specialty health care	8 (40.0)	10 (50.0)	2 (10.0)	4.65
3. Occupational Therapy	10 (50.0)	5 (25.0)	5 (25.0)	4.60
4. Speech Therapy	12 (60.0)	4 (20.0)	4 (20.0)	3.90
5. Physical Therapy	11 (55.0)	7 (35.0)	2 (10.0)	3.90
6. Nutrition counseling	10 (50.0)	45.0	5.0	3.90
7. Scoliosis screening	11 (57.9)	7 (36.8)	1 (5.3)	3.53
8. Special Equipment or Braces	11 (57.9)	7 (36.8)	1 (5.3)	3.53
9. Dental care	10 (50.0)	10 (50.0)	0	3.50
10. Eyeglasses / Contacts	10 (52.6)	7 (36.8)	2 (10.5)	3.37
11. Vision screening	12 (60.0)	8 (40.0)	0	3.20
12. Developmental screenings	14 (70.0)	5 (25.0)	1 (5.0)	3.05
13. Hearing Aids	15 (75.0)	4 (20.0)	1 (5.0)	2.75
14. Emergency health care	16 (80.0)	3 (15.0)	1 (5.0)	2.60
15. Primary health care	16 (80.0)	3 (15.0)	1 (5.0)	2.20
16. Hearing screening	18 (90.0)	1 (5.0)	1 (5.0)	2.15
Other: augmentative communication; deaf interpreters; services for children with autism				

Scale: 1 = "it is very easy or no problem to get the service"

10 = "it is very hard or nearly impossible to get the service"

B. Ease of accessing community-based services

- Key informant participants were provided a list of community-based services that might be needed and used by children and youth with special health care needs and their families. Participants were instructed to rate how hard it was for children and youth with special health care needs and their families who live in their area to obtain these services if they needed them. The rating scale was 1 to 10, "1" meant "it is very easy or no problem to get the service" and "10" meant "it is very hard or nearly impossible to get the service".
- Services are listed in order of hardest to easiest to access services based on mean scores. Ties were broken based on the percentage of respondents who rated the service in the 8-10 range, indicating these were among the hardest services for families to obtain for their children.

Table 2. Ease of accessing community-based services for children and youth with special health care needs, listed in order of hardest to easiest to access services

Service	Rating 1-3 N (%)	Rating 4-7 N (%)	Rating 8-10 N (%)	Mean Rating
1. Transportation assistance for medical or dental appointments	1 (5.6)	7 (38.9)	10 (55.6)	7.61
2. Good quality summer/out-of-school care	2 (10.0)	7 (35.0)	11 (55.0)	7.45
3. Respite care	2 (11.1)	6 (33.3)	10 (55.6)	7.44
4. Good quality child care / day care	2 (10.0)	8 (40.0)	10 (50.0)	7.00
5. Good quality after school care	2 (10.5)	10 (52.6)	7 (36.8)	6.42
6. Recreational opportunities	3 (15.0)	11 (55.0)	6 (30.0)	6.10
7. Support for families (training, support groups)	4 (20.0)	10 (50.0)	6 (30.0)	5.95
8. Transition planning (to adult health care)	6 (30.0)	8 (40.0)	6 (30.0)	5.60
9. Special Education services (3 to 21 years)	11 (55.0)	7 (35.0)	2 (10.0)	3.75
10. HeadStart/Pre-K programs (3 to 5 years)	10 (52.6)	9 (47.4)	0	3.58
11. Care coordination / case management / service coordination	13 (65.0)	7 (35.0)	0	2.85
12. Early Intervention programs (birth to 3)	16 (80.0)	4 (20.0)	0	2.00

Scale: 1 = "it is very easy or no problem to get the service"

10 = "it is very hard or nearly impossible to get the service"

C. Barriers

- Respondents were provided a list of potential barriers that families with children and youth with special health care needs might face in obtaining services (things that make it harder for them to get what they need). They were asked to indicate which of these issues were barriers experienced by families in their area.
- Barriers are listed below in the order of most frequently mentioned (most widespread barriers) to least frequently mentioned (area-specific barriers).
 1. No transportation
 2. Providers not available
 3. Services too expensive
 4. Lack of child care
 5. Can't afford co-pays and deductibles
 6. Difficulty understanding what insurance provides
 7. Insurance didn't cover services or providers
 8. Did not know where to go
 9. Cannot afford to lose pay
 10. Missed School Days
 11. Unable to take time off
 12. Waiting list for services too long
 13. Hours/Location of providers not convenient
 14. Language and cultural barriers
 15. State policy or administrative barriers
 16. Denied services by providers
 17. No insurance

IV. Greatest Needs and Biggest Barriers

- Respondents were asked to discuss their perceptions of the three biggest barriers families in their area faced in accessing services for their children. They were also asked to share their views on the three greatest service needs for CYSHCN and families in their area.
- The three most frequently mentioned “greatest needs” were:
 1. Transportation
 2. Respite Care
 3. Child care (daycare, summer/out-of-school care, and after school care combined)
- Other needs that were mentioned by multiple respondents were for mental health/behavioral services, especially for children with autism spectrum disorder, and access to pediatric specialty care providers.
- The three most frequently mentioned “biggest barriers” were:
 1. Lack of transportation
 2. Systems navigation issues, including lack of knowledge of resources and lack of parental involvement or motivation
 3. Lack of access to pediatric specialty health and health-related service providers
- Other barriers that were mentioned by multiple respondents were lack of child care, insurance and financial issues, language barriers, and waiting lists.
- The discussion related to barriers and needs yielded overlapping themes, which are presented below.

A. Services (Health/Medical and Community)

Respite and child care (day care, after school care, and summer/out-of-school care) were the services that participants reported to be the most difficult to access. Recreational opportunities were also highlighted as an area in which access could be improved.

Specialist care including medical, health-related (PT, OT, Speech), mental and behavioral health, and dental services were repeatedly noted as major needs in the community around the state. Barriers to these services included waiting lists and insurance limitations.

Early Intervention and Care Coordination services were identified as particularly easy to access. Overall, however, community-based services were rated as more difficult to access compared to health services. Interview participants noted a lack of education, awareness, and advocacy regarding disability in general. Participants also observed that low levels of parental education and socioeconomic status frequently impacted children’s care.

Interview respondents highlighted the need for family support services such as trainings and group meetings

B. Transportation

Transportation was rated hardest to get among community-based services. It was also listed as the biggest barrier to care and the most frequently cited need. In particular, transportation access for rural areas was identified as a need. More funding to support transportation and more timely reimbursements were also noted as needs related to financial assistance for transportation. Participants noted that even if a family has a vehicle, if that vehicle is not outfitted for wheelchair lifts or with other adaptations, it cannot be used to accommodate a child’s physical disabilities.

C. System of Care

Interview respondents noted several areas of the system of care that made navigation and access difficult for families. Participants perceived families as becoming overwhelmed and confused by the current system. Specific barriers relating to the system of care mentioned in the interviews included: long waiting lists, administrative barriers, language barriers, and limited provider selection/availability. Overall, respondents noted that a lack of knowledge about eligibility and where to go to seek out services made it difficult for families to navigate the system. Participants indicated that perceptions of system challenges may be based on a lack of awareness or knowledge about the services provided by CRS, including care coordination.

D. Education

Respondents rated Early Intervention, PreK/HeadStart, and special education services as easier to access than many other services in the system of care. Communication between schools and families was noted as an area in which improvements were needed, especially related to the Individualized Education Plan (IEP) process and understanding which services a child was eligible to receive. Respondents also highlighted a need for better connections between entities such as Early Intervention and school systems.

E. Financial/ Insurance

Financial strain was a concern voiced across all topic areas of the interviews. Interview participants noted that a major barrier in receiving necessary care for children with special health care needs was the costs associated with parents or caretakers taking time off work. Basic financial assistance for expenses such as power/utility bills was also identified as a need. Respondents were concerned about the cost of services or equipment that are frequently not covered by insurance but necessary to provide the best service to the child.

F. Future Planning and Transition

Interview participants indicated an awareness of the need for transition planning, though it was not a primary concern for the majority of respondents. Participants highlighted the need for care coordination throughout the lifespan and the need for innovations and a “clearer path” with respect to transition services, especially related to vocational rehabilitation services.

V. Strengths, Challenges, and Lessons Learned

Overall, participants actively engaged in key informant interviews. Participants added richness to the discussion of issues facing children and youth with special health care needs and their families. Responses provide extensive and powerful information to guide the identification of needs and potential solutions. Successful completion of key informant interviews across the breadth of CRS coverage areas was greatly enhanced by the process used by CRS. Specifically, CRS asked local staff members to identify and communicate with potential key informants prior to their being contacted by UAB. This increased the participant’s understanding of the importance of the interview and why they were selected as a key informant. However, as with all qualitative interview data, these findings are likely not generalizable to all members of the population or to other states/regions. Readers are cautioned to consider these findings in addition to those from other methods and data from the 2015 needs assessment to best triangulate issues and needs.

CRS Focus Groups

Report of Focus Groups regarding Children and Youth with Special Health Care Needs and their Families
Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
A portion of the 2015 Title V Maternal and Child Health Needs Assessment
Completed by UAB School of Public Health, Department of Health Care Organization and Policy



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I. Introduction

Children's Rehabilitation Service (CRS) implements Alabama's children with special health care needs program, mandated by Title V of the Social Security Act. As a part of requirements to receive federal funding, a comprehensive needs assessment is required every five years. To plan and conduct its 2015 Title V Maternal and Child Health (MCH) Needs Assessment, CRS entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB). Part of that agreement was to plan, facilitate, analyze, and report on focus groups conducted with representatives of children and youth with special health care needs (CYSHCN) and their families in Alabama.

CRS and UAB together developed a strategy to identify groups that were representative of the geographic diversity of the state and included the perspectives of CYSHCN and their families. This report presents the perspectives of families with CYSHCN and youth with special health care needs (YSHCN). The final Alabama 2015 Maternal and Child Health Needs Assessment Report includes information from all MCH populations in the state (pregnant and child bearing age women, infants, children and adolescents, and CYSHCN).

II. Methods

UAB facilitated focus groups consisting of family members of CYSHCN and YSHCN to determine their opinions on needed health and health related services, the state's service capacity, and strengths and weaknesses in the health care delivery system.

A. Number and Location

A total of five focus groups were held throughout the state: one for fathers, one for Hispanic families, one for youth with special health care needs, and two for English-speaking families. Focus group locations included the following cities in Alabama: Birmingham, Gadsden, Montgomery, Selma, and Dothan. Focus groups were conducted July – September 2014. Because attendance was low at the youth focus group, structured interviews were conducted with four additional youth (identified by the CRS State Youth Consultant). These interviews were conducted at locations convenient for the youth interviewees.

B. Recruiting, logistics, and incentives

CRS staff members were actively involved in recruiting families and youth for the focus groups. The CRS internal leadership team determined the cities for the focus groups and then assigned a local CRS staff member to assist with logistics and to recruit families. The focus group for Hispanic families was planned with the local CRS staff member, and recruitment was conducted by an interpreter who was known to the target population. All focus group sessions were facilitated by UAB faculty, supported by UAB staff and/or graduate students, with the exception of the focus group for Hispanic families, which was facilitated by a physician in Adolescent Medicine who was also a graduate student in the UAB School of Public Health, Maternal and Child Health Concentration. This session was supported by UAB faculty and other graduate students. All events were held at neutral locations known by and easily accessible to the participants.

Groups consisted of between two and 13 members, and each session lasted approximately 1 ½ hours. Through a partnership with Family Voices of Alabama, participants were provided a \$25 cash stipend, mileage reimbursement, and assistance with child care as needed. All focus group sessions were digitally recorded and professionally transcribed by a third-party vendor. Recordings from the Hispanic focus group were transcribed in Spanish and then translated into English. Transcripts were reviewed by the focus group facilitator for each respective group to ensure accuracy.

C. Interview guide development

Building upon previous interview scripts provided by CRS and discussion of important topics of interest, UAB faculty developed discussion guides for the focus groups. Separate focus group scripts were developed for the youth and family focus groups. The interview guide for the Hispanic group was translated into Spanish by a third-party vendor.

D. Participant demographics

There were 31 participants across all focus groups and youth interviews. An optional survey was provided for participants to identify specific demographic characteristics about themselves. The following chart describes the demographics of participants who chose to complete the survey (Family n = 24; Youth n = 6).

		Family Focus Groups N (%)
Race	Black/African American	11 (45.8)
	White	10 (41.7)
	Hispanic	3 (12.5)
Education	Less than high school	5 (20.8)
	High school/GED	4 (16.7)
	Some college	5 (20.8)
	Associate's degree	2 (8.3)
	Bachelor's degree or higher	8 (33.3)
Family Income	Less than 10,000	9 (45.0)
	\$10,000 - \$29,000	3 (15.0)
	\$30,000 - \$69,000	4 (20.0)
	\$70,000 or more	4 (20.0)
		Youth Focus Group/Interviews N (%)
Race	Black/African American	4 (66.7)
	White	2 (33.3)
Education	Still in high school	3 (50.0)
	High school/GED	1 (16.7)
	Still in college	2 (33.3)

E. Data analyses

Starting with the focus group guides, UAB faculty identified general topical areas, or broad codes, to categorize data from transcripts. Under supervision of UAB faculty, each transcript was then reviewed by two UAB doctoral students to identify and classify transcript data based on the broad codes. Upon completion and verification, each transcript was then reviewed to identify smaller focus areas, or fine codes, within the broad codes. UAB doctoral students verified coding rules with one another and resolved discrepancies through discussion with UAB faculty. Data were analyzed by hand and also through the use of NVivo software.

III. Findings

Findings are presented by theme. Within each area, sample quotations are also included.

A. Experience of CYSHCN and Families

Not surprisingly, families expressed that they differed from families with typically-developing children for a variety of reasons. These reasons centered on the level of involvement they must have in their child's life as he or she ages and the amount of time and energy they invest to coordinate and advocate for their child in terms of medical care, education, and other day-to-day considerations.

Family dynamics were integral to the experiences of participants, particularly how having a child with special health care needs affected their relationships with their other, typical children. Parents used the word “balance” repeatedly when discussing family, time, expenses, work, and their children. Nevertheless, families, particularly grandparents, provided significant support to children with special health care needs and their caregivers.

Several parents reported moving away from areas with more services to be closer to the support of family. Youth participants noted that while they may experience the world differently, they had strong friendships and were comfortable in self-advocating for their own needs. However, youth participants reported experiencing frustration from the lack of control of their own time (in terms of appointments and services) and, on occasion, their own mobility.

“It changes the way you are with your other people in your house too because you have to try and balance it especially if you have other children and not put all your attention on one child at the expense of your other child.”

- Parent respondent

“I can say the most disrespectful and hurtful thing I ever have to deal with is when I’m out in public, you know, I get the strange looks. I’ve had people ask me what’s wrong with him, you know. Can he talk? For a single day sometimes it does anger me, but I learn to tune it out. I learned not to put myself in their shoes, you know, to their level, and be like you know what, they’re not in my shoes they don’t even know what I go through every day.”

- Parent respondent

“Being a person with a disability you are on everybody else’s time all the time especially when you want to do something. You have to wait on them. You have to wait until they get up, you have to wait until they feel like taking you to such and such place. A lot of times with that, I end up being late for my obligations.”

- Youth respondent

“It’s kind of that double standard, “Oh, because you’ve got a disability, you’re not free to make your own choices. You’re not free to live your life,” so to speak. People are always trying to dictate how they think a person with a disability should act or what they should be like. And you can’t put us in a box like that because a lot of people try to put people with a disability – a lot of people that don’t know, they feel like we all act the same and all think the same way and that’s not the case.”

- Youth respondent

B. Community

Families noted that support and services in the community are frequently lacking and do not meet their needs. While they highlighted schools and churches generally, and more specifically, CRS, Alabama Institute for the Deaf and Blind (AIDB), and Alabama Disabilities Advocacy Program (ADAP) as strengths, parents were quick to note that they often felt isolated and unable to access the services their children need. Many of these perceptions seemed to be rooted in an urban/rural divide. Parents recommended offering regular and regional meetings or service fairs to bring awareness to what is available for children with special health care needs and suggested that these activities would help break down communication barriers.

Families also expressed a need to build support and connections among families and between families and service providers to improve communication about and coordination of services. Parents noted that these support networks were important to them as they often felt misunderstood or shamed by people in the community who did not understand their situation. Youth participants noted that they felt both independent and included by people in their community.

"I don't know that I've ever seen another child with a hearing aid besides just maybe on Facebook and these friends that we did have, this one couple we met, they've moved. So I think the support groups are lacking. And being able to talk to other parents like you were saying, about what's going on."

- Parent respondent

"They don't understand what autism is. I think none of my family. I try to explain to them. I even took some of them with me to the therapist so they can explain it. Still like-- They never heard or never had anyone in the family to have it. So they don't understand. But my grandmother, she understands. And the church do, too. The church that I go to, they understand also."

- Parent respondent

"At school they see them differently, because they have their disability and they are not seen as a normal child."

- Parent respondent

C. System of Services

Participants overwhelmingly communicated difficulties in navigating the system of care for children with special health care needs. General barriers included the time it takes to navigate as well as the perceived bureaucracy and conflicting information. Families were often unable to access services based on schedules and distance to providers. Overall, parents viewed CRS positively as facilitators for the process; however, they noted that barriers still exist for those who need additional help or who are unaware of CRS's availability. According to family participants, more facilitation or parent training for navigating the system is needed.

Repeatedly, parents and youth highlighted the need to be proactive when interacting with the system of care in order to have needs met. Cultural challenges existed within the system of care as well. A number of participants identified racial or ethnic stigma or stigma associated with receiving Medicaid and other government benefits. In particular, Hispanic participants noted their experiences of prejudice and heightened challenges in navigating the system. Hispanic participants also expressed a need for Spanish-speaking service providers and facilitators.

"The person who was interpreting began to get angry with us and she said, 'You don't understand anything!'"

- Parent respondent

"You go to see a doctor and he tells you, 'I don't know you.' Or when you go to a hospital, they look at you as if you weren't a person ...About a month ago I went to the hospital with my daughter but she has Medicaid and they don't pay any attention."

- Parent respondent

"I think as a parent, you have to kind of-- I feel like you're walking uphill all the time because you just kind of have to search and fight for the information where it's not, you know, sometimes I feel like you have to fight for things a lot for services and the information."

- Parent respondent

"Yeah, it takes a lot of digging and a lot of time."

- Parent respondent

"You can call that [Social Security Office] number seven times and get seven different answers."

- Parent respondent

"You need to be proactive and do it yourself."

- Parent respondent

"[CRS] steps in where other agencies should."

- Parent respondent

D. Medical and Health Services

Families of children with special health care needs reported using a wide variety of medical and health-related services ranging from primary and specialty care and dental and mental health services. While the types of specialists families need to access varied by type and severity of their children's disability and/or needs, uniformly, participants in the focus groups noted limitations to accessing specialty care services other than CRS clinics in regions outside of the state's larger metropolitan areas.

Participants reported that travel distances to reach these specialists were a burden. Families reported using their pediatricians or primary care providers as their "first line[s] of defense" when they were unable to access specialists. Families reported challenges related to a lack of provider knowledge in treating children with special healthcare needs and limited time with providers to sufficiently address their child's needs. Parents noted that ADRS and CRS were helpful in breaking down some barriers and improving access to needed services. Hispanic participants expressed a need for Spanish-speakers at the practice level as well as better cultural competence among all health providers.

"We have a wonderful pediatrician and he is our first line of defense that we go to him and let him check her out. I think that's the thing with Medicaid now. You have to see your pediatrician even though he cannot do anything about neurology, you have to go and physically-- He has to physically see the child and then you go, even though you know you need to see the neurologist. You have to stop at the pediatrician first. But specialized services you have to travel."

- Parent respondent

"You can tell that [my doctor's] usually used to dealing with elderly people with high blood pressure and back problems."

- Youth respondent

"Her primary care doctor they have some...nursing care system, but they only send them out for maybe fifteen-twenty minutes once a week or sometimes twice a week and that's just to get them a bath."

- Parent respondent

"CRS is pretty much it."

- Parent respondent

E. Other Services

Among participants, there were varying perceptions regarding the availability and quality of non-medical or health-related services in the community. Early Intervention and respite care services were widely sought by families that saw value in these supports. However, families indicated that they would like to access more of these services either through more visits or a broader geographic distribution.

The greatest need that families identified was child care for children with special healthcare needs, especially care that was both high quality and affordable. Some families noted that more support groups or advocacy groups were needed. Recreational opportunities such as swimming classes and the Special Olympics exist in some areas of the state, but overall, they are not meeting the needs of families. Focus group participants also noted that they turn to churches to meet a large portion of their needs. Participants were not aware of family counseling opportunities outside of sessions conducted in the context of the foster care system. Notably, among Hispanic participants, there was a very low level of awareness of specific services as well as CRS itself.

"Respite is definitely needed. Funding for respite because like I said, there's a waiting list and they'll say, 'Well, we don't have very many nurses that do pediatric patients.' Well, you need to hire some because moms need a break."

- Parent respondent

"They have no activities going on. I can take them to the park or something or get on the swings but other than that, like, anything for special need kid you can got do whatever you want them to have fun."

- Parent respondent

F. Financial and Insurance

Not surprisingly, finances and insurance coverage were frequently identified concerns of parents. Uniformly, parents reported the high costs of having a child with special healthcare needs. Parents expressed a desire to provide their children with high quality services and supports but noted that coverage limitations and high out-of-pocket costs often made it difficult to do so. While Medicaid is one of the primary mechanisms that these families have for paying for care, focus group participants reported challenges related to types and amount of services covered and a dearth of quality providers accepting Medicaid.

Among participants, there was a lack of awareness regarding Alabama Medicaid's pending transformation/reform to Regional Care Organizations. While awareness of the Affordable Care Act was high, stakeholders seemed uncertain of its potential impact. Families reported mixed experiences; some were seeing premium increases while others were seeing decreases or no changes. Youth participants expressed a general lack of knowledge of who paid for their care, as well as their coverage and benefits. Some expressed a desire to learn more about the process or planned to learn more as they grew older. Hispanic participants' knowledge of All-Kids (Alabama's Children's Health Insurance Program), Medicaid, and the Affordable Care Act was limited or absent. There was a great deal of confusion among these Hispanic participants about what healthcare options were available to them.

"You have to wait until you have the money."

- Parent respondent

"Sometimes the medications are too expensive and we have to find the way to buy them."

- Parent respondent

"My daughter needs to use insoles and the doctors have told me that the footwear she needs is expensive so sometimes it's difficult because I would like to buy something not so expensive but I have to make an effort to buy that footwear she needs."

- Parent respondent

"Most of the really good doctors don't accept Medicaid. They only accept Medicare. So it's like I don't own Medicare, I don't even think I qualify for Medicare. So it's like I have to suffer because my insurance."

- Youth respondent

G. Future Planning and Transition

Overall, families reported a lack of conversation and guidance about transition planning. Those that had begun thinking of transition services focused predominantly on financial and legal services over healthcare. Furthermore, families noted that providers were not initiating conversations about these issues and that families must seek out resources themselves.

Youth participants expressed clear thoughts about their future educational and professional plans but indicated a reliance on a variety of advocates and resources including teachers/professors and parents for guidance. Youth reported dissatisfaction with their experiences with transition resources, especially related to the lack of individualized planning based on their interests versus what someone thought they could or should do. Some youth were unaware of any formal transition plan. When asked whether youth were given opportunities to speak to physicians privately without parents in the room, responses were mixed, with some parents and youth indicating there had been opportunities provided for private conversations while others reported this had not been available to them.

"What would happen if something happened to me?"

- Parent respondent

“Early Intervention helps you transition. I feel like my Early Intervention coordinator kind of is holding my hand through and saying, “Okay, here’s the next step.” Which is amazing because I wouldn’t know what to do or what to ask for.”

- Parent respondent

“We talked to an attorney but we did it on our own. No one told us to do it.”

- Parent respondent

“Nobody’s going to take care of your child as good as you are. There’s some great people in this world, CRS, Bell Center. There’s some great people but at the end of the day you can’t rely on those kind of people will be around in every daily activity.”

- Parent respondent

“I wish there was more opportunity for people with disabilities as far as the general – regular working world. Because the selection is so thin for us, you know? Because people don’t like to hire people with disabilities, especially in this state. Some people see us as a liability. We don’t like to think about that but it’s true.”

- Youth respondent

H. Staying Healthy

Respondents associated “being healthy” with exercise and eating healthy and appropriate foods. Families with children who had specific nutritional needs noted that it could be a challenge to access the necessary formula/food within the current system. Youth participants reported that they typically received information about staying healthy from their physicians, family members, therapists, and trainers. Youth discussed aspects of healthy dating/friendship relationships, preparing for safe sexual encounters, and described risky behaviors such as smoking, drugs, or drinking as areas to avoid in order to be healthy. For these topics, youth noted that their primary sources of information are parents, friends, the internet, and their school.

“Being healthy is very important because it’s already a struggle being a person with a disability. And by not being healthy, you’re aiding that struggle – you’re enabling yourself. So being healthy, it helps you overcome some of your obstacles that you have being a person with a disability. It helps you be independent and helps you – and by independent, I mean it helps you to move freely from place to place.”

- Youth respondent

“For people with disabilities, I don’t feel like it’s talked about at all because a lot of people assume that we can’t have sex anyway.”

- Youth respondent

I. Emergency Preparedness

Only a few families reported having a documented preparedness plan or kit. Some respondents communicated a general concept of preparedness or pieces of plans, however, few if any had written documentation or formal plans in place. A number of participants viewed their experiences of managing medical emergencies as strengthening their resilience to ability to handle emergency situations. In emergency situations, families said they expect to experience challenges related to coordinating with medical providers, accessing records, and ensuring that prescriptions are filled/available. Those with strong relationships with a social worker or other care coordinators viewed these individuals as important contacts. Participants expressed a desire for more knowledge and awareness about these issues and care coordination specific to their needs.

“I really don’t think that’s something that I’ve really thought about. It would be helpful maybe to have some information or a seminar or something, saying have you thought about this.”

- Parent respondent

“In my case, I have never had an emergency, but I think that if I had one my social worker has told me that when something like that occurs, I can call her and she will call the emergency service of the community.”

- Youth respondent

J. Education

Although it is not directly under the purview of CRS, quality educational opportunities and easily navigable processes were high on the list of priorities for families of children with special health care needs. Children were receiving a variety of services in the schools from aides to specific therapies (speech, physical therapy, occupational therapy), and many families reported high levels of dissatisfaction with their interactions with educational service providers or the quality of the services themselves.

Many families noted that the IEP process is a tedious and tension-filled experience. Others described the process as confusing and burdensome. Youth participants reported satisfaction with their ability to integrate into the typical academic experience, and several noted that they had participated in their own IEP meetings. Hispanic participants expressed a need for Spanish-speakers at the school level to help communicate needs and coordinate services. A number of youth also expressed concern regarding how to pay for college.

"I'm almost scared of the process because you have to fight....It scares me to think that they're pushing back. Your child doesn't need that when I just felt like it's going to be an uphill battle."

- Parent respondent

"Sometimes at school there isn't anybody who can speak Spanish so we can't communicate, and in case they had some kind of support we don't get to know about it because we don't know the language."

- Parent respondent

"Knowing how the system works before your child gets in there because they will take advantage of anything that they realize that you're not aware of."

- Parent respondent

"Funding for school. I wish it was more clear what the stipulations were. Because it seems like every time I pass a stipulation, they've got another stipulation. So I wish that was more clear."

- Parent respondent

"I feel like if a child needs some aid that person needs to know how to work with the special need child not just put a person there because she or he needs a job."

- Parent respondent

K. Transportation

Consistent with previous needs assessments, transportation was a frequently cited barrier by both families of children with special healthcare needs and the youth themselves. Travel times and distances were noted as barriers to accessing medical care, services, and school/educational programs. Many participants relied on public transportation. Where public transit exists, limited schedules and routes hindered the ability of families and youth to move around their environment.

When public transit is unavailable, participants reported using a variety of alternative modes of transportation including: taxis, Greyhound buses, friend or neighbors' cars, and rental cars. While this barrier was frequently described as a rural/urban divide, some families noted that the lack of quality public transportation in metropolitan areas prevented them from being able to reach providers and services "across town". High gas prices were also a consideration for participants. Youth respondents expressed a desire to learn to drive. Some had had a seamless and positive experience with the available services in the state for learning to drive adapted vehicles, while others experienced more challenges accessing these types of services.

"We have very limited public transit. And it's only available Monday through Friday and you do have to call in advance. And there's only a couple of buses that I think they actually have that are wheelchair accessible. You have to call in advance. So if you have an emergency and you need to get to a doctor and you have a person that's in a wheelchair, unless you have a friend or a neighbor or someone, you're kind of out of luck with that."

- Parent respondent

"If the [mother] doesn't know how to drive she has to wait for her husband and if the husband works or if they don't have transportation they don't know where to turn to, or single women won't be able to do it because they have to stay 24 hours a day with the kids."

- Parent respondent

"My mom used to have a jeep with a lift on it, but she doesn't have that anymore, so we have to rent a van to like go to the doctor and stuff."

- Youth respondent

L. Social Media

Parents and youth reported using a variety of social media ranging from Facebook and Twitter to Instagram and blogs. Furthermore, they identified similar motivations for using these resources. Respondents used social media to connect with friends and family as well as other families and individuals experiencing the same medical conditions. Families and youth suggested that social media tools helped to build informal support networks. Respondents indicated that they did not use social media to interact with health professionals.

IV. Strengths, Challenges, and Lessons Learned

Overall, there was active participation and attendance for the focus groups, though the youth focus group had to be supplemented with structured interviews due to low attendance and the limitation of only one planned session. Participants readily engaged with one another and added richness to the discussion of issues facing children and youth with special health care needs and their families. Responses provided extensive and powerful information to guide the identification of needs and potential solutions.

Based on the experiences of implementing these focus groups, it is clear that having a local liaison that is knowledgeable, well-connected, and trusted by the community is critically important to planning and recruiting participants. Without this key person, challenges of recruitment would likely outweigh abilities and resources for implementation. The findings gathered through this process are likely to broadly represent the viewpoints of Alabama's CYSHCN and their families. However, as with all qualitative focus group data, these findings are likely not generalizable to all members of the population or to other states/regions.

The UAB needs assessment team member assigned to support and guide each local liaison instructed him or her to recruit from both inside and outside CRS and to broadly include multiple special health care need types and family demographics to promote generalizability. Still, most participants were likely a convenience sample as funding and time limitations precluded broad community recruitment. As CRS is such an integral part of the system of services for children and youth with special health care needs and their families, especially in smaller, rural areas, most focus group participants received services themselves, had received services in the past, or had children who were currently receiving services. Readers are cautioned to consider these findings in addition to those from other methods and data from the 2015 needs assessment to best triangulate issues and needs.



Knowledge that will change your world

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