CHILDREN'S
Rehabilitation Service

2025

Title V

Maternal and Child Health Services Block Grant

Comprehensive Needs Assessment

Focus on Children and Youth with Special Health Care Needs

ADRS
Alabama Department of
REHABILITATION SERVICES

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Introduction & Purpose

The Alabama Department of Public Health (ADPH) serves as the lead agency for the state's Title V Maternal and Child Health (MCH) Block Grant, a federally mandated initiative requiring annual applications and a comprehensive statewide needs assessment every five years. The administration of Alabama's Title V MCH Block Grant program is unique in that ADPH's Bureau of Family Health Services division oversees four of the five MCH population domains (groups established through the federal legislation). These are the Women/Maternal, Perinatal/Infant, Child, and Adolescent domains. Children's Rehabilitation Service (CRS), a division of the Alabama Department of Rehabilitation Services, oversees the fifth domain, Children and Youth with Special Health Care Needs (CYSHCN).

The purpose of the statewide needs assessment is to identify priority MCH issues and guide strategic planning efforts. The primary goal is to improve MCH outcomes and to strengthen state, local, and community partnerships in addressing the needs of Alabama's MCH population. The findings from this statewide assessment, together with prioritized needs and aligned measures, provide a framework against which progress can be assessed during the 2025-2030 Title V MCH Block Grant reporting period.

Based on the needs assessment, states must prioritize seven to 10 MCH needs, aligning at least one to each of the MCH population domains. From a national list, states must select at least one National Performance Measure (NPM) for each MCH population domain, assuring that the selected NPM aligns with making progress toward addressing the prioritized need. States may also develop State Performance Measures (SPMs) to address any prioritized need that does not adequately align with NPMs. Alabama's 2025 Title V MCH Needs Assessment culminated in the selection of **eight state priority needs**, which are addressed through **six NPMs** and **three SPMs**.

This report focuses only on the portion of the needs assessment related to CYSHCN. Process, methods, data sources, prioritization, priority needs, and aligned measures are only presented for this domain. For a report of the full Title V MCH Needs Assessment, including all MCH population domains, visit the Alabama Department of Public Health at https://www.alabamapublichealth.gov/mch/index.html.

Needs Assessment Process & Methods

Overview

The FY 2025 Title V MCH Needs Assessment was collaboratively conducted by ADPH and CRS. Due to the organizational structure of Title V MCH in the state, there were two separate, but related processes for the needs assessment. Both ADPH and CRS entered into contractual agreements with the University of Alabama at Birmingham (UAB) School of Public Health's Applied Evaluation and Assessment Collaborative (AEAC) to facilitate the implementation of the needs assessment process. UAB AEAC also partnered with community-based organizations to

support community engagement during the assessment. These organizations included the Alabama Network of Family Resource Centers (ANFRC), Family Voices of Alabama (FVA), United Ability (UA), and United Cerebral Palsy of Huntsville (UCP-H).

Both ADPH and CRS established Needs Assessment Leadership Teams and convened Advisory Committees to support planning and implementation of the needs assessment, as well as responding to the findings to support prioritization and strategic planning. Staff from ADPH and CRS participated on each other's committees, and there was some overlap of key partners and community representatives on the advisory groups.

Community, Family, & Stakeholder Engagement

To accurately identify and address the needs of a state's MCH population, it is essential to engage community members, families, and other stakeholders from the outset, as well as maintain their involvement throughout the needs assessment process. As such, both the ADPH and CRS needs assessment processes included strategies for ongoing stakeholder engagement and to assure equitable opportunities for participation. These included:

- Convening needs assessment leadership teams and advisory committees
- Partnering with trusted local community-based organizations for recruitment and awareness efforts
- Using social media and press releases to encourage participation in needs assessment data collection methods
- Distributing marketing materials in English and Spanish
- Collaborating with agency local staff, parent consultants, and partners to promote distribution of data collection methods and encourage participation
- Partnering with community-based organizations to support community participation in focus groups
- Facilitating diverse focus groups that included representation based on geography, race, ethnicity, language, income, age, and disability status
- Using translation and interpreter services for focus groups (Spanish and American Sign Language [ASL])
- Fielding mobile-friendly online surveys in English and Spanish
- Assuring accessibility of online surveys for screen reading software

Data Collection Methods & Sources

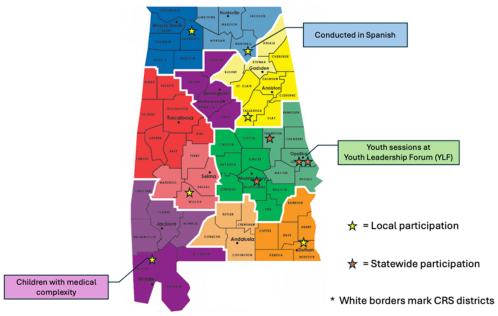
While there were some differences in approach, both ADPH and CRS worked with UAB AEAC to review and summarize Federally Available Data (FAD), which are key MCH indicators and trend analyses provided to states annually based on national, population-based surveys. FAD represent national priority areas that are important MCH health outcome and systems measures. The most recently available data were reviewed and synthesized for each MCH population domain, comparing Alabama's performance to U.S. averages and Alabama trends over time. When possible, these data were reviewed to identify any differences in outcomes based on common sociodemographic characteristics.

Additionally, UAB AEAC supplemented FAD with new data gathered through community, family, and stakeholder engagement. These quantitative (numbers) and qualitative (stories, experiences) data were synthesized to identify potential priority need topics. As discussed below, all needs that emerged were considered through a two-phase process to finalize the state's priority need list and guide state action planning.

CRS

In addition to FAD, CRS also included the following data collection methods and sources:

- Three years of data from two CRS client and caregiver surveys focused on:
  - Transition to adulthood and adult health care services
  - Care coordination services
- Consensus scoring documents from three years of the *Family Engagement in Systems Assessment Tool (FESAT)*
- Web-based survey for healthcare providers, families, and adolescents
- Community focus groups
- Listening sessions held during existing events and meetings
- Key informant interviews (representatives from local and state agencies and public and private organizations serving CYSHCN and their families)

Federally Available Data (FAD)	Survey	Focus Groups & Listening Sessions	Key Informants	Other Existing Information
Key MCH indicators provided to states These are National Performance Measures	427 Responses (Online, English & Spanish) Role (Respondents could select all that apply.) • Parent/Caregiver of CYSHCN = 225 • YSHCN = 58 • Health Care/Health-Related Care Provider = 86 • Teacher/Childcare Provider = 59 • Advocacy or Community Support Organization = 36 • State Agency Employee = 35	8 Focus Groups & 2 Listening Sessions <u>Focus Groups</u>: • Parents/ Caregivers of CYSHCN – English = 5 • Parents/ Caregivers of CYSHCN – Spanish = 1 • Youth/ Young Adult with SHCN = 2 <u>Listening Sessions</u>: • Alabama Hands and Voices (40+ families of children and teens) • CRS State Parent Advisory Committee (20+ Local Parent Consultants and Local Parent Advisory Committee Members)	9 Participants • Health and Health-Related Care Providers (rural pediatrician, nurse practitioner, school therapists) • Rural Teacher, Secondary Grades • Health Care Equipment Vendors • Advocacy & Community Organization Staff	• CRS Transition Survey • CRS Care Coordination Survey • CRS FESAT Consensus Scoring	

Description of Prioritization Process

UAB collaborated closely with ADPH and CRS to co-facilitate a two-phase process to prioritize identified needs. Phase One involved advisory committee members, partners, and staff reviewing synthesized data and potential priority needs to provide feedback using criteria that ADPH and CRS established as important for final decision-making related to the identification of a priority needs list. Phase Two incorporated the broader Phase One feedback with additional decision criteria to allow the ADPH and CRS leadership teams to finalize the selection of priority needs for further action.

Phase One: UAB AEAC presented synthesized data and identified needs to the CRS Needs Assessment Advisory Committee and partners to facilitate preliminary selection of priority needs. Through a full-day meeting, more than 60 individuals with an interest in CYSHCN participated, representing state and community organizations, family-led groups and family leaders, advisory committee members, and key CRS staff, including parent consultants. The meeting featured both large and small group discussions, which fostered deeper engagement and generated valuable strategic ideas and partnership opportunities to support the next five-year Title V MCH Block Grant cycle. Using a 5-point Likert scale of 1 (low) to 5 (high), participants rated each need based on three decision-making criteria:

- **Importance based on data**
    - Importance of addressing need based on all data presented, including numbers (quantitative) and themes from experiences and opinions shared by families, youth, and providers (qualitative)
    - Includes consideration of comparisons to national outcomes, state trends over time, and disparities in outcomes (unequal outcomes for some groups)
- **Alignment with other state priorities and efforts**
    - The extent to which the issue/need aligns with other priorities and efforts in the state
    - The extent to which the issue/need has "momentum" in the state or is a "hot topic" that others are talking about and working on
    - The extent to which working on the issue/need would create opportunities to partner with other groups to expand efforts to address the topic
- **Potential for effective approaches or solutions**
    - The extent to which potential solutions or approaches exist to address the issue/need
    - Based on your professional knowledge and experiences, the extent to which there are strategies that work or can work with appropriate leadership, funding, and attention

Using a QR code, attendees entered ratings into a form hosted on the Qualtrics survey platform that calculated average ratings for each need on each decision criterion, as well as the sum of all three. The average of the summed decision criteria ratings was used to establish the preliminary rank order of the identified needs for the CYSHCN population domain.

Phase Two: UAB AEAC facilitated a half-day session with the CRS State Office Leadership Team to review synthesized data and preliminary rankings of needs from Phase One and to determine the final priority need list for the CYSHCN domain. This final list was established via consensus through discussion guided by the following decision criteria:

- **Importance based on data**
    - Based on all data (qualitative and quantitative)
    - Considering comparisons to nation/region, trends over time, and unequal outcomes
    - Considering family and provider stories

    - Considering advisory group ratings and preliminary rankings
- **Effective interventions or potential solutions**
    - Are there evidence-based or evidence-informed solutions/interventions?
- **Feasibility**
    - How feasible is it to address the need?
        - Based on cost, expertise, time, resources, political will, existence of solutions, and whether addressing the need is within CRS scope and control
- **Alignment with other priorities and initiatives in the agency**
    - Is there alignment with other CRS priorities?
- **Opportunities to collaborate with national, state, and/or community partners**
    - Are there opportunities to work with others at national, state, and/or community levels?
- **Data/Method to assess availability**
    - Do we have (or can we get) data to measure and monitor progress on addressing the need?

Final List of Priority Needs

Using the previously described process, CRS selected a total of three priority needs to contribute toward the full MCH state priority need list and then aligned them with performance measures to guide improvement efforts to serve as the foundation for developing Alabama's State Action Plan. The following table presents the state priority needs aligned with selected measures for the CYSHCN population domain:

Priority Need	National or State Performance Measure	MCH Population Domain
Comprehensive Care Coordination and Supports for System Navigation	NPM: Medical Home, CYSHCN	CYSHCN
Transition to Adulthood	NPM: Transition to Adult Health Care	CYSHCN
Family and Youth Peer Supports	SPM: Emotional Support with Parenting	CYSHCN

Though the additional identified needs for the CYSHCN domain were not included in the final list, CRS leadership felt that in addressing the selected priority needs, many of these other needs could be addressed directly or indirectly through comprehensive strategies aligned under the selected NPMs and newly developed SPM. Synthesized data summaries and all identified needs are shared in the Appendices of this report with the intention that partner organizations and other groups can use the information to guide their work. Both ADPH and CRS identified broader systems and community factors that influence health. While these were not directly included in prioritization, these are recognized as foundational considerations in the development of strategies that will support outcome improvements for all of Alabama's MCH populations.

Appendices: CYSHCN Population Domain Report

This section includes the comprehensive CYSHCN-specific report that guided the needs prioritization and selection process. This report contains a synthesis of all data – previously existing and newly gathered – that were included in the 2025 Title V MCH Needs Assessment. Based on these data, need topics were identified for the CYSHCN population domain.

CYSHCN

The table below presents the **need topics** that were identified for CYSHCN in Alabama presented in rank-order based on the summed average score from all raters during Phase One of the prioritization process.

Rank	Need Topic	Average Phase One Score
1	Comprehensive Care Coordination and Supports for System Navigation	12.03
2	Access to Health and Health-Related Services and Equipment	12.00
3	Transition to Adulthood	11.57
4	Access to Community Services and Supports	11.26
5	Medical Home	11.16
6	Adequate Insurance and Financial Supports	11.14
7	Special Education Services and Integration into School Systems	11.10
8	Health Teaching and Information Needs	10.71
9	Family and Youth Peer Supports	10.69
10	Transportation and Geographic Isolation	10.38
11	Family and Youth Engagement	10.22
12	Community Factors that Influence Health Outcomes	9.64

More detailed descriptions for these need topics and synthesized data aligned with them are presented in the **CYSHCN-specific report**, which begins on the next page.

Selected State Priority Needs and Aligned Measures

During Phase Two of the prioritization process, three state priority needs were selected for the CYSHCN Population Domain for the 2025-2030 Title V MCH Block Grant cycle:

- **"Comprehensive Care Coordination and Supports for System Navigation"**
- **"Transition to Adulthood"**
- **"Family and Youth Peer Supports"**

Three measures were aligned to track performance in addressing these needs.

National Performance Measure: Percent of children with (and without) special health care needs, ages 0 through 17, who have a medical home
National Performance Measure: Percent of adolescents with (and without) special health care needs, ages 12 through 17, who received services to prepare for the transition to adult health care
State Performance Measure: Percent of children with special health care needs, ages 0 through 17, whose parent receives emotional support with parenting

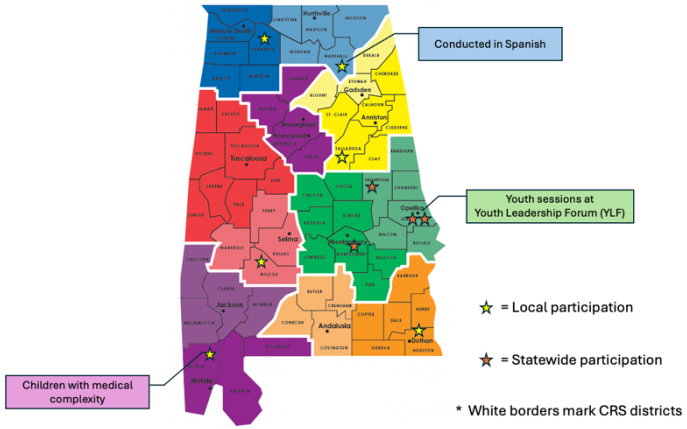
Title V Maternal and Child Health Services Block Grant and Needs Assessment Overview

The Title V Maternal and Child Health (MCH) Block Grant Program is a federal-state partnership that is a key source of support for promoting and improving the health and well-being of the nation's families, including women, adolescents, infants, children, and children and youth with special health care needs. One requirement for funding is that every five years states must conduct a comprehensive needs assessment to identify priority issues of the MCH population.

The needs assessment is a systematic process to collect information about the State's public health system and service provision to women, pregnant women, mothers, infants, children, adolescents, and children and youth with special health care needs. The information collected is used to identify statewide priorities, drive strategic planning, and allocate funds. The goal is to improve MCH outcomes by aligning evidence-based strategies with the identified priority needs of the MCH population.

Needs Assessment Methods

Children's Rehabilitation Service partnered with the Applied Evaluation and Assessment Collaborative at the University of Alabama at Birmingham School of Public Health to conduct the 2025 needs assessment. Family Voices of Alabama, United Ability, and United Cerebral Palsy-Huntsville partnered to support focus groups.

Federally Available Data (FAD)	Survey	Focus Groups & Listening Sessions	Key Informants	Other Existing Information
Key MCH indicators provided to states These are National Performance Measures	427 Responses (Online, English & Spanish) Role (Respondents could select all that apply.) • Parent/Caregiver of CYSHCN = 225 • YSHCN = 58 • Health Care/Health-Related Care Provider = 86 • Teacher/Childcare Provider = 59 • Advocacy or Community Support Organization = 36 • State Agency Employee = 35	8 Focus Groups & 2 Listening Sessions <u>Focus Groups</u>: • Parents/ Caregivers of CYSHCN – English = 5 • Parents/ Caregivers of CYSHCN – Spanish = 1 • Youth/ Young Adult with SHCN = 2 <u>Listening Sessions</u>: • Alabama Hands and Voices (40+ families of children and teens) • CRS State Parent Advisory Committee (20+ Local Parent Consultants and Local Parent Advisory Committee Members)	9 Participants • Health and Health-Related Care Providers (rural pediatrician, nurse practitioner, school therapists) • Rural Teacher, Secondary Grades • Health Care Equipment Vendors • Advocacy & Community Organization Staff	• CRS Transition Survey • CRS Care Coordination Survey • CRS FESAT Consensus Scoring	

CYSHCN

Domain Summary (Need topics and key findings synthesized based on all data sources.)

Need Topic	Key Findings	Statewide CYSHCN Survey[1]	Focus Groups & Listening Sessions	Key Informant Interviews	Federally Available Data[2]	CRS Programmatic Data
Access to Community Services and Supports	• Inadequate and unequal access to and availability of community services and supports, especially in rural areas. • These are services and supports that foster quality of life and engagement in daily activities outside of addressing medical or health care needs, including respite care, recreational opportunities, and childcare programs that are trained to support CYSHCN and willing to accept them.	X	X	X	No FAD indicator	X
Access to Health and Health-Related Services and Equipment	• Inadequate and unequal access to and availability of health and health-related services, in-home supports, medical equipment, and supplies, especially in rural areas and for people whose first language is not English.	X	X	X	No FAD indicator	X
Adequate Insurance and Financial Supports	• Inadequate insurance, including financial strain from out-of-pocket costs, benefit limits, non-covered items, and complicated processes for approvals and waivers.	X	X	X	X	
Community Factors that Influence Health Outcomes	• Unequal experiences of community factors that influence health outcomes, overall and specifically for families of CYSHCN. • These are system and community issues that influence health and well-being, including high cost of living, unsuitable housing, lack of housing modifications and accessible homes, financial strain and difficulty maintaining employment, and food insecurity.		X	X	X	X
Comprehensive Care Coordination and Supports for System Navigation	• Insufficient or unequal assistance to help families navigate the system of care, including identifying providers, programs, family supports, and community resources. • Inconsistent comprehensive care coordination that includes topics beyond health medical needs, including services/supports that address quality of life, engagement in daily activities, and the non-medical drivers of health.	X	X	X	X	X
Family and Youth Engagement	• Inconsistent opportunities for families and youth to engage in policymaking and the design, delivery, and evaluation of programs and policies.		X		No FAD indicator	X

CYSHCN

Family and Youth Peer Supports	• Lack of opportunities to create "community" for families, caregivers, and youth. • Lack of peer support – including coping, mental health, and emotional support – and opportunities to learn from each other and share resources.		X	X	No FAD indicator	
Health Teaching and Information Needs	• Lack of (accurate) information about specific conditions and disabilities. Lack of awareness of policies, rights, and processes. • Lack of preparation for families to engage in partnerships with professionals who work with their children/youth and to participate in shared decision-making about their care.		X	X	No FAD indicator	
Medical Home	• Lack of or inadequate access to comprehensive medical homes, including comprehensive care coordination, streamlined referrals, and communication across systems/between providers. • Inconsistent medical provider knowledge about CYSHCN and specific conditions. Inconsistent provision of health care that focuses on overall well-being and quality of life versus clinical care only. • Lack of preparation of the medical provider workforce to provide family-centered care, engage in partnerships with families, and participate in shared decision-making with them about the care of their children.		X	X	X	
Special Education Services and Integration into School Systems	• Insufficient special education services and integration into school systems, including before- and after-school programs, teacher and para-teacher training, unequal accommodations, and truancy/absenteeism policies.	X	X	X	No FAD indicator	X
Transition to Adulthood	• Inadequate supports for transition to all aspects of adulthood, including health care, education, employment, community programs, and independent/supported living.	X	X	X	X	X
Transportation and Geographic Isolation	• Lack of or unequal ability to access health and community services due to lack of transportation and/or geographic location.		X	X	No FAD indicator	X

[1] Ranking in Top 5 issue list for any respondent role group. [2] A FAD indicator related to this topic has a value that is worse compared to U.S., a worsening state trend, and/or unequal outcomes.

Statewide Survey

Out of 427 total responses, the following issues were ranked as challenges affecting Alabama CYSHCN, their families, and the providers who serve them. Responses are broken down by respondent role group. Respondents could select all role groups that apply to them.

Issue	Rank[3]						
	Overall	Parent/ Caregiver of CYSHCN (n=220)	Youth with SHCN (n=56)	Health Care or Health-Related Care Provider (n=83)	Teacher or Childcare Provider (n=59)	Advocacy or Community Support Organization (n=35)	State Agency Employee (n=35)
Access to community services and supports	1st	1st	1st	2nd	1st (tie)	1st (tie)	1st (tie)
Quality early childhood programs that are safe and affordable, especially for children with disabilities	2nd	3rd	2nd	1st	1st (tie)	1st (tie)	3rd (tie)
Help for families to navigate the system of care	3rd	2nd	3rd	3rd	3rd	3rd	1st (tie)
Special education services	4th	4th	6th	4th	5th	8th	3rd (tie)
Access to health and related services	5th	5th	4th (tie)	6th	4th	4th	9th
Transition to adulthood	6th	6th (tie)	4th (tie)	7th	7th (tie)	5th	6th (tie)
Adequacy of insurance	7th	8th	8th (tie)	5th	6th	6th	10th (tie)
Accessibility and accommodation supports	8th	6th (tie)	7th	10th	9th	7th	6th (tie)
Provider workforce that is knowledgeable about CYSHCN	9th	9th	8th (tie)	8th	7th (tie)	9th (tie)	3rd (tie)
Transportation	10th	12th (tie)	11th (tie)	9th	10th	9th (tie)	6th (tie)
Integrated technology, medical records, and data to support continuity of care and data-informed decision-making for program planning and evaluation	11th	10th	11th (tie)	12th	11th	13th	10th (tie)
Shared decision-making and partnerships between families and health-related professionals	12th	11th	10th	14th	12th	12th	12th
Family and youth involvement and participation in advisory groups, program development, policymaking, and systems-building activities	13th	12th (tie)	11th (tie)	13th	13th (tie)	9th (tie)	13th (tie)
Comprehensive medical homes	14th	14th	11th (tie)	11th	15th	15th	13th (tie)
Youth with SHCN not meeting physical activity and nutrition guidelines	15th	15th	15th	15th	13th (tie)	14th	15th

*Issue list based on needs identified in previous 2020 needs assessment and do not directly match need topics identified in current 2025 needs assessment.

[3]Based on number and percentage of respondents who selected issue as one of their top five concerns. Yellow highlight identifies Top 5 issue for respondent group.

Federally Available Data

Indicator		Value[i]	Comparison to U.S.	State Trend
National Performance Measures				
Food Sufficiency[4] (0-11 years)	All	61.8%	Worse (lower)	Decreasing (worsening)
	CYSHCN	54.8%	Worse (lower)	Decreasing (worsening)
Housing Instability[5] (0-11 years)	All	20.5%	Worse (higher)	Unavailable
	CYSHCN	29.9%	Worse (higher)	Unavailable
Bullying – Victimization[6]	All	33.5%	Comparable	Stable
	CYSHCN	47.8%	Comparable	Decreasing (improving)
Transition to Adult Healthcare[7]	All	15.5%	Comparable	Stable
	CYSHCN	23.2%	Comparable	Increasing (improving)
Medical Home[8]	All	50.9%	Better (higher)	Stable
	CYSHCN	46.5%	Better (higher)	Increasing (improving)
Medical Home – CYSHCN Personal doctor or nurse[9]		78.0%	Comparable	Decreasing (worsening)
Medical Home – CYSHCN Usual source of sick care[10]		78.3%	Worse (lower)	Decreasing (worsening)
Medical Home – CYSHCN Family-centered care[11]		78.7%	Worse (lower)	Increasing (improving)
Medical Home – CYSHCN Referrals[12]		75.1%	Better (higher)	Increasing (improving)
Medical Home – CYSHCN Care coordination[13]		66.0%	Better (higher)	Increasing (improving)
Standardized Measure				
Adequate Insurance[14] (0-17 years)	All	74.6%	Better (higher)	Stable
	CYSHCN	72.1%	Better (higher)	Stable

Color Key: = statistically worse = statistically better = concerning trend

[i] Data and analyses provided to states by Maternal and Child Health Bureau (https://mchb.tvisdata.hrsa.gov/Home/FADDocuments) from the National Survey of Children's Health (NSCH 2022-2023)

Indicator Note	Groups Experiencing Unequal (Worse) Outcomes[ii]
4	**ALL**: 6-11 years; CYSHCN; household education less than college graduate; Medicaid, uninsured; <400% Federal Poverty Level (FPL); Black
5	**ALL**: 6-11 years; CYSHCN; household education less than college graduate; Medicaid, uninsured; <400% FPL; Black, Hispanic
6	**ALL**: CYSHCN; household education high school graduate; Medicaid; <100% FPL; female **CYSHCN**: Medicaid; female
7	**ALL**: Non-CYSHCN; Medicaid; <100% FPL **CYSHCN**: Medicaid; <100% FPL (limited data due to sample size)
8	**ALL**: 0-5 years; CYSHCN; CYSHCN with more complex health needs; household education high school graduate or less; Medicaid; uninsured; <100% FPL; Black, Asian, Hispanic; language other than English **CYSHCN**: 0-5 years; CYSHCN with more complex health needs; Medicaid; <100% FPL; Black (limited data due to sample size)
9	**CYSHCN**: Medicaid; <100% FPL; Black (limited data due to sample size)
10	**CYSHCN**: 0-5 years; Medicaid; <100% FPL; Black (limited data due to sample size)
11	**CYSHCN**: <100% FPL; Black (limited data due to sample size)
12	**CYSHCN**: Private insurance; 200-399% FPL (limited data due to sample size)
13	**CYSHCN**: 0-5 years; private insurance; 200-399% FPL (limited data due to sample size)
14	**ALL:** 12-17 years; CYSHCN; private insurance

[ii] Analyses for unequal outcomes for CYSHCN are limited by small sample size in the national dataset. Not all listed outcome differences are statistically significant. All differences are reported to show concerning trends.

CYSHCN

Focus Groups and Listening Sessions

Access to Care	• **<u>Health-Related Services and Equipment</u>**
	  ○ **Access to Health Care Services**: Difficulties accessing specialty care (neurologists, nephrologists, adult physicians), therapies (PT, OT, SP, ABA), dental care (especially for children with Medicaid), and autism diagnostic services.
	  ○ **Access to Medical Equipment** (wheelchairs, gait trainers, assistive communication devices) **and Therapies**: Frustrating, slow, bureaucratic process, which often requires multiple trips to providers resulting in additional copays and leads to delays in receiving essential services; importance of loaner medical equipment.
	  ○ **Access to Medical Supplies**: Complex, time-consuming, and inefficient process to obtain monthly supplies creates risk for gaps in essential care.
	  ○ **Mental and Behavioral Health Services for CYSHCN**:
	  ▪ CYSHCN often faced additional mental and behavioral health challenges, such as managing emotions, coping with stress, and dealing with social interactions.
	  ▪ Insufficient services, long wait lists, and limited availability of specialized care, with limited services outside of crisis care.
	  ○ **Mental and Behavioral Health Services and Support for Caregivers**: Caregiving burden and financial strain can lead to depression, stress, and feelings of isolation. Need for respite care or breaks for caregivers to care for themselves too.
	  ○ **Challenges in Obtaining Services, Equipment, and Supplies**:
	  ▪ Limited providers, long wait times, travel distances, geographic barriers.
	  ▪ Copays, insurance coverage issues/lack of coverage, frequent insurance denials, complex paperwork, slow approval processes.
	  ▪ Lack of provider awareness.
	  ○ **Language Access**: Importance of accommodating language needs to support access to care; inconsistent or inadequate interpreter services and translated materials.
	• **<u>Community Services and Supports</u>**
	  ○ **Childcare Challenges**:
	  ▪ Lack of childcare options for CYSHCN – especially with older children – including after-school, summer, and school closure/e-learning days.
	  ▪ Lack of training for childcare providers to care for CYSHCN, including tube-feeding, behavioral issues, basic care.

	▪ Some programs are unwilling to take CYSHCN or require paying for a full week to get one day of care. ▪ Reliance on individual sitters to provide childcare. ▪ Challenges keeping a job due to lack of childcare. ○ **Respite Care Needs**: Families with medically fragile children struggle to find adequate and affordable respite care options. ○ **Limited Recreational Activities**: Lack of local recreational activities for CYSHCN to keep children engaged and active.
Adequate Insurance and Financial Supports	• **Financial Burden**: Out-of-pocket expenses for uncovered medical supplies, equipment, therapies, and medicines cause stress, financial strain, and challenges with cost of living. There is a lack of expendable income to purchase what public and private insurance doesn't cover. • **Access and Usability Issues**: Gaps and barriers to essential care are created by complex paperwork/application processes; insufficient coverage; claim denials (even with accompanying letters of medical necessity); slow approval processes; and delays in receiving services, supplies (including monthly/recurring supplies), and equipment. • **Medicaid Challenges**: Application for Medicaid waiver and financial assistance programs is complex and time-consuming, requiring extensive paperwork. Medicaid reimbursement rates have not increased since 2012, causing financial strain for providers.
Community Factors that Influence Health	• **Financial Burden**: Families face financial strain and stress due to overall cost of living, made worse by high cost of care, out-of-pocket medical expenses, copays, and items not covered by Medicaid or private health insurance. Despite available assistance, many families still face significant financial burdens. • **Work Limitations**: Difficulty maintaining employment due to the demands of caring for their children, further impacting financial stability. Limited flexible work options and employers who understand that caring for a CYSHCN often requires parents to take time off work for appointments and illness. • **Housing Challenges**: Concerns about inadequate housing conditions, long waiting lists for accessible housing, difficulties affording better housing options, and lack of affordability with long waiting lists for housing modifications.
Comprehensive Care Coordination and Supports for System Navigation	• **Challenges for Families**: ○ Difficulty coordinating care, navigating complex systems, and ensuring continuity of services. ○ Greater challenges in receiving comprehensive care coordination for children with more medical complexity. (continued on next page)

	• **System Navigation Issues**:
	  ○ Lack of clear and timely information, uncertainty about where to seek support, and concerns about knowing what to ask to access services.
	  ○ Concerns about having to "know about" services and resources or "know what to ask" to access services and resources or have questions answered.
	  ○ Concerns about lack of referrals and/or information between programs or resources CYSHCN might qualify for (CRS, EI, VRS, school systems, therapies), which results in "missed opportunities."
	• **Needs for Improvement**:
	  ○ Better communication and collaboration among providers, agencies, and community organizations to support families and improve care coordination.
	  ○ Lack of continuity in care and support once students age out of the school system.

Family and Youth Peer Supports and Engagement in Policy	• **Support for Parents and Caregivers**: Emotional and mental health support, community support groups, and peer networks are crucial for parents and caregivers.
	  ○ Feelings of isolation and stress and the need for breaks.
	  ○ Struggles with managing their own mental health while caring for their children.
	  ○ Comfort in sharing experiences with others who understand parent/caregiver challenges.
	  ○ Importance of providing resources, education, information, training, and peer support to parents and caregivers to help them navigate the challenges of caring for their CYSHCN.
	• **Needs of CYSHCN**: Quality of life includes access to recreational activities, peer relationships, and community involvement.
	  ○ Need for building community connections, more opportunities for social interaction, and inclusive programs and activities.
	  ○ Importance of opportunities for CYSHCN to be around other CYSHCN like them, including those who use sign language.
	  ○ Older CYSHCN face difficulties in forming friendships and finding appropriate peer activities.
	• **Family and Youth Engagement in Policy**: Parents/caregivers want to be aware of rights, rules, and laws and have experiences to share with policymakers to support policy change/improvement.
	  ○ Parents/caregivers are leaders at many levels and have valuable experiences and ideas to share with lawmakers and systems that serve CYSHCN.
	  ○ Parents/caregivers advocate for policy change in communities, including inclusion in school systems, childcare programs, and recreational opportunities.

Health Teaching and Information Needs	• **Information Gap**: Caregivers may be unaware of Early Intervention services, CRS, and other available programs and resources. Caregivers may lack knowledge of specific therapies and treatments and how

	they could benefit their children. Some words and terms that are used may be confusing and hard to understand, limiting caregivers' ability to choose services that best fit their child's needs. • **Need for Education and Outreach**: More education and outreach are needed for families and providers about available resources, services, and rights. • **Advocacy Challenges**: Families often need to advocate strongly for their children, sometimes facing resistance from schools and institutions.

Medical Home	• **Healthcare Provider Challenges**:
	  ○ Difficulty finding doctors familiar with CYSHCN conditions and disabilities, as well as the therapies and services they may need.
	  ○ Providers are often unfamiliar with the available resources, services, programs, and other supports that may benefit CYSHCN and their families.
	  ○ Not enough time in appointments to ask questions and receive detailed explanations.
	  ○ Need for consistent healthcare provider who understands child's medical history and needs.
	  ○ Need for healthcare providers who consider the overall quality of life for CYSHCN, not just their medical needs.
	  ○ Importance of hospitals and healthcare providers directing families to programs like CRS and Early Intervention when they first suspect an issue with children.
	• **Information and Support Gaps**: Lack of information for new parents about available resources and programs, often forcing them to rely on word of mouth.
	• **Need for Coordinated Care**:
	  ○ Many families experience difficulties in coordinating care, navigating complex systems, and ensuring continuity of services.
	  ○ Need for a central healthcare provider to manage and coordinate various services (therapies, specialist care, equipment), ensuring continuity and considering the overall quality of life for CYSHCN.
	  ○ Need for better communication and collaboration among providers and agencies to support families more effectively.

Special Education Services	• **Quality and Access**:
	  ○ Concerns about the quality and accessibility of special education services.
	  ○ Complicated IEP processes, feelings of being overwhelmed in meetings, and having to fight for services and inclusion.
	• **Teacher Needs**: Teachers need to be knowledgeable, approachable, and supportive. Lack of training for teachers and childcare providers to care for CYSHCN.

	• **School Supports**: Schools need to provide adequate support and accommodations, consistent curricula, and opportunities for socialization. Concerns related to inconsistencies in how well schools integrated CYSHCN. • **Resource Needs**: Increased funding is needed for special education, including teachers, therapists, paraeducators (especially in rural areas), and ABA services. ○ Not enough school system therapists, with low frequency of visits, group sessions, and summer skill loss. Lack of school therapists and services, gap in services for children who do not qualify for school therapy but still need support.
Transition to Adulthood	• **Transition Challenges**: Lack of residential options, community supports, and appropriate services for young adults with SHCN after leaving the school system. Lack of local activities and day programs to keep youth engaged and learning once they transition out of school systems. • **Healthcare Concerns**: Challenges finding suitable adult doctors familiar with CYSHCN diagnoses and conditions. • **Legal Issues**: Concerns about preparing youth for lifelong care, including issues such as guardianships, wills, and trusts. • **Life Skills and Independence**: Importance of learning life skills like managing finances, finding housing, managing a household (cooking, cleaning), basic hygiene care, and achieving career goals, along with the need for support and motivation.

Transportation and Geographic Isolation	• **Transportation Barriers**:
	  ○ Transportation is a major barrier for some families, particularly in rural areas, due to the need to travel to larger cities to access the services and providers their children need.
	  ○ Difficulties in finding reliable and flexible transportation, impacting healthcare access and regular attendance for appointments and therapy sessions.
	  ○ Frustration with the difficulty of booking transportation services in advance with no immediate options available.
	  ○ Difficulty using gas cards and lengthy approval for Medicaid travel reimbursement.
	• **Financial Burden and Scheduling Issues**:
	  ○ Expenses related to long-distance travel for healthcare, including gas and time away from work.
	  ○ Challenges in getting appointments after school and work, with the drive time causing children to miss school.
	• **Accessibility Issues**:
	  ○ Lack of wheelchair-accessible transportation options (vans, public transit) hinders access to essential services.
	  ○ Purchasing personal accessible vehicles is often cost-prohibitive.

Quotes

"I wish it was not so hard – as a new parent, I didn't really know what I was doing, but I felt like it was a mistake and there were many IEP meetings that I went to and I just felt like – I don't know. I felt like if I really – I wish that I could go back and fight harder for her to be in a regular classroom, but why should I have to fight so hard? Why can't our children be given the same opportunity to learn and not be – I don't know."

"I just want to say that things like this are important [speaking about the focus group session]. Prior to COVID, our school used to host a coffee and chat, and we would get together the special needs parents because you might be going through potty training a special needs child that might have physical or emotional or mental handicaps that are creating a little bit different of an issue than maybe a typical child. Being able to talk to someone that has been through it before. Having this, being able to sit and just discuss it and find out about other resources but also connect to families, I think is definitely beneficial and would also help get some of that information out if they could host more events and more things like that."

"If I could make a blanket rule of, "Don't ask me my child's diagnosis. Ask me what symptoms we need to be seen for." Because the moment they hear the diagnosis. … 'Oh, it's just she's disabled.' She's a human being with emotions … Or, if you don't have a specific diagnosis, they won't see you. If we could take that diagnosis off and go by symptoms – that's my magic wand moment."

"Most families are already under stress because of inflation, health insurance/healthcare cost concerns, and work-life balance. When you add CYSHCN, the stress can be a breaking point for families. Families need holistic support that takes into consideration an array of variables that affect whole families."

"Well, my daughter, she has a feeding tube, so we was having to go to Birmingham to get it changed because they didn't have the right person down here at (location), so it was constantly goin' to Birmingham 'cause her tube comes out so much, like once a month or maybe two times a month."

"It is a little bit challenging to obtain all of the supplies that she needs. Her supplies are G-tube-related diapers, wipes, underpads, and then suction supplies, oxygen supplies. That, then there's medications. Then there's doctor visits, appointments, all that. It just at times becomes very overwhelming just to have to coordinate all of it every month. Some of those, if you miss a day or a deadline, you're going into a weekend – potentially a holiday weekend – without things that (she) cannot live without. That is a challenge."

"Another thing that was resonating with the panel here is our kids' self-esteem and their mental health. We focus so much on their physical stuff and their accommodations that we are not conscientious about how things are going emotionally and mentally and that's something that we're leaving on the table and not addressing that as much as we're addressing the (condition)."

"Our boys go to therapy once a week. They are having to miss – what, five weeks? Because their insurance won't cover their last five weeks. For us to do it, it's like – For us to pay for their five weeks, it's $399 per kid a week. We have five weeks that we're not gonna have any therapy whatsoever. It's gonna be like starting all over with our oldest."

"I recently found out this week that I have to go and apply through the court system for guardianship for medical care for my 18-year-old. He's turning 19. I understand the law, but I was told I need to come up with $2,800 and go have a conversation so I can go in front of a judge. I have two kids that I'm gonna to have to do this for. I don't think any of us have the money sitting around just to walk up and be like, 'Hey, let's go do this.' "

The Children and Youth with Special Health Care Needs (CYSHCN) portion of Alabama's Title V Maternal and Child Health Needs Assessment was led by staff from Children's Rehabilitation Service (CRS), a program of the Alabama Department of Rehabilitation Services.

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ACKNOWLEDGEMENT:

CRS would like to acknowledge and thank our community partners who supported this needs assessment:

- Family Voices of Alabama
- United Ability
- United Cerebral Palsy Huntsville

For any additional questions about the CYSHCN portion of the Alabama Needs Assessment, please contact Stacey Neumann.

CRS leadership would like to thank all staff for their many contributions throughout the needs assessment process. CRS would also like to thank Alabama Department of Rehabilitation Services Commissioner Jane Elizabeth Burdeshaw for her continued support. CRS thanks our community partners, Family Voices of Alabama, United Ability, and United Cerebral Palsy Huntsville, for their ongoing support of the CYSHCN program, including the needs assessment. Many thanks to the UAB Applied Evaluation and Assessment Collaborative team for their guidance and exemplary support during the process. Most importantly, CRS would like to thank all the families and youth that completed the surveys and participated in the focus groups and key informant interviews. *"We could not do this without their support."*

CHILDREN'S
Rehabilitation Service

This needs assessment was conducted by faculty and staff from the Applied Evaluation and Assessment Collaborative within the Department of Health Policy and Organization at the University of Alabama at Birmingham (UAB) School of Public Health.

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