

# Children's Specialized Hospital Community Health Needs Assessment

September 2025

PREPARED BY  
HEALTH RESOURCES IN ACTION

**RWJBarnabas**  
HEALTH

Children's  
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#### **Questions**

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# Executive Summary

## Introduction

In 2025, Children’s Specialized Hospital (CSH) undertook a community health needs assessment (CHNA) process. The purpose of the CHNA was to identify and analyze community health needs and assets among children, youth, and young adults with special healthcare needs and their families in New Jersey and prioritize those needs to inform strategies to improve community health.

## Methods

The 2025 CSH CHNA utilized a comprehensive data collection approach focused on the social determinants of health and applying a health equity lens. The CHNA process used a mixed-methods, participatory approach that engaged agencies, organizations, and those with special healthcare needs and their families. The CHNA process was guided by the CSH CHNA Advisory Committee, which included community representatives. Methods of data collection included:

- Reviewing existing data on social, economic, and health indicators in New Jersey.
- Conducting a targeted survey for those living and working with special needs children and young adults (637 participants).
- Facilitating one virtual focus group with nine individuals including parents/caregivers who participate in CSH’s Family Advisory Council and their young adult children.
- Conducting eight key informant interviews with ten stakeholders from a range of sectors.

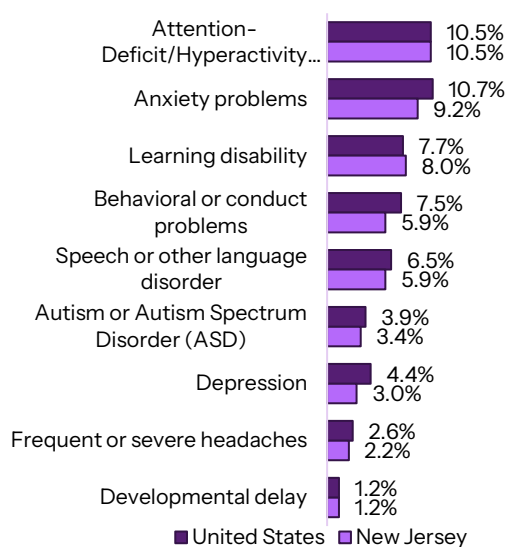
## Findings

The following provides a brief overview of key findings that emerged from this assessment:

### Population Characteristics

- **Demographics.** The total population of New Jersey is slightly over 9 million and approximately 30% of this population is under age 24. A majority of residents self-identify as non-Hispanic White (51.9%), followed by residents who self-identify as Hispanic (21.9%) and non-Hispanic Black (12.3%).<sup>1</sup> CSH has locations in several of New Jersey’s most racially and ethnically diverse counties including Essex, Hudson, Middlesex, Passaic, and Union.
- **Population of Children with Special Healthcare Needs.** About 20% of children under age 18 in New Jersey have special

**Percent Children Aged 3-17 Years with Current or Lifelong Condition, by United States and New Jersey, 2022-2023**



DATA SOURCE: National Survey of Children’s Health, 2022-2023

<sup>1</sup> U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023.

healthcare needs.<sup>2</sup> Attention-Deficit/Hyperactivity Disorder (ADHD), anxiety, and learning disabilities are the most common special healthcare conditions among children ages 3-17 in New Jersey.

### Community Social and Economic Environment

- **Community Strengths and Assets.** Interviewees and survey respondents shared that New Jersey has many resources to support children and youth with special healthcare needs and their families. There are numerous healthcare services: in addition to CSH, community survey respondents reported that their children receive services from various specialized and children's hospitals. In addition, the state has four long-term care facilities for children/youth, including two operated by CSH. CHNA participants stated that New Jersey also has other supportive organizations including advocacy and education organizations, and referral and coordinating agencies. State agencies fund New Jersey's Children's System of Care; the Division of Vocational Rehabilitative Services (DVRS) and the Intellectual and Developmental Disabilities (IDD) program provide employment, educational, and everyday living support for youth and young adults. Participants also reported that state and local organizations, including schools and community-based nonprofits, offer sports, recreational, education, and transition programs for children and youth.
- **Education.** Special education data from the NJ Department of Education show that 225,333 students ages 6 to 21 received special education services in New Jersey.<sup>3</sup> School districts provide a variety of services to support students including occupational therapy (OT), physical therapy (PT), and speech, among others. Assessment participants expressed concern about the impact of federal and state budget cuts on special education services, including out-of-district placements and hiring of special education teachers, and shared that lack of communication between education and healthcare systems creates barriers to accessing appropriate school-based services.
- **Employment and Workforce.** Data from the Bureau of Labor Statistics show that unemployment rates in New Jersey declined from a high during the pandemic and have remained steady in recent years at slightly over 6%.
- **Income and Financial Security.** While median household income in New Jersey is high (\$126,827), slightly over 10% of families with children under age 18 live below the poverty line.<sup>4</sup> Several focus group and survey respondent parents/caregivers talked about the economic challenges associated with caring for children with special healthcare needs. They mentioned the cost of equipment, which is not always covered by insurance, as well as expenses associated with therapies, transportation, and housing. Focus group parents and survey respondents also stated that camps and sports and enrichment programs can be costly for families and eligibility for financial support is limited. Finally, for some

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<sup>2</sup> National Survey of Children's Health, 2022-2023. NCSH defines Children and Youth with Special Healthcare Needs (CYSHCN) as "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

<sup>3</sup> Thomas, N., Paul, S., Bach, S., & Houtenville, A. (Eds.) (2024). Annual Disability Statistics Compendium: 2024 (Table 13.1). Durham, NH: University of New Hampshire, Institute on Disability.

<sup>4</sup> U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023.

families an additional cost is paying for legal assistance to obtain school-based services or out-of-school placements from their school districts.

- **Food Access and Food Insecurity.** CSH Community Survey data about food insecurity indicate that 7.7% of respondents who were parents/caregivers of special needs children often worried about whether their food would run out before they got money to buy more, while 26.7% of respondents indicated that they sometimes worried about this. Data from the CSH SDOH screening survey indicate that 23.7% of CSH families surveyed between January and September 2024 were food insecure.<sup>5</sup>
- **Housing.** Housing costs can be a burden for families, especially given the cost of living in New Jersey. American Community Survey data indicate that 38.0% of homeowners and 62.3% of renters spend 30% or more of their household income on housing.<sup>6</sup> Data from the CSH SDOH screening survey conducted in 2024 identified that 4.6% of CSH families were without steady housing and another 9.6% were concerned with losing their current housing.<sup>7</sup>
- **Transportation.** Transportation was reported to be a challenge for some families with special needs children. Difficulty utilizing public transportation with special needs children, the need for specialized vehicles, and problems scheduling and accessing existing transportation services for those with special needs were cited as challenges. Parent and young adult focus group participants frequently mentioned that lack of transportation hindered their young adult children's ability to access employment as well as social and recreational opportunities.

### Community Health Issues

- **Obesity, Healthy Eating, and Physical Activity.** National Survey of Children's Health data indicates that a far higher proportion of children with special healthcare needs are overweight (14.3%) than other children (6.2%).<sup>8</sup> Fewer special needs children engage in regular physical activity.
- **Mental Health and Behavioral Health.** As in past CHNAs, mental health was identified as a challenge for families with special needs children in 2025. Over half of parent/ caregiver survey respondents identified behavioral/mental healthcare as very hard or hard to access in their communities. Barriers to accessing mental health services shared by assessment participants include waitlists, lack of providers willing to take new patients or accept Medicaid. Lack of mental health services for young adults who have aged out of pediatric services is also a challenge. Parents/caregivers also shared challenges finding mental

*"Mental health, such as psychology and psychiatry, to the extent which the patient needs, is extremely hard to find after a diagnosis or referral."*

– Young adult community survey respondent

<sup>5</sup> Data collected from 17,048 screenings, conducted January – September 2024.

<sup>6</sup> U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019–2023.

<sup>7</sup> Data collected from 17,048 screenings, conducted January – September 2024.

<sup>8</sup> National Survey of Children's Health, 2022–2023.

health providers who have expertise working with children and youth who have intellectual or developmental disabilities. Schools also play a role in supporting student mental health; however, these services have been cut back as school budgets have tightened.

- **Environmental Health.** About 1.8% of children in the state of New Jersey had elevated blood lead levels in 2022.<sup>9</sup> This proportion is higher than the 0.6% of New Jersey children with elevated blood lead levels reported in the 2022 CHNA.
- **Maternal and Infant Health.** About 8% of births in New Jersey in 2018–2022 were to babies weighing under 2500 grams (low birthweight).<sup>10</sup> In 2023, 31.9 births per 10,000 in New Jersey had neonatal abstinence syndrome (NAS).<sup>11</sup>

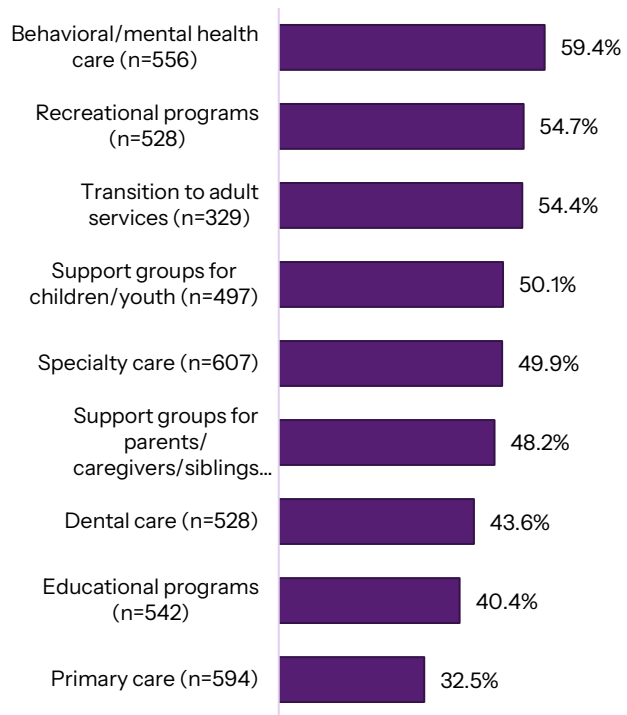
### Access to Services

CSH survey respondents identified behavioral/mental healthcare, recreational programs, and transition to adult services as hardest to access for children with special healthcare needs, similar to CHNA survey results from 2022. Challenges accessing recreational and behavioral/ mental health programs were the top two concerns among Hispanic parent/caregiver respondents and those with younger children. Finding programs to support transition to adult services was the top challenge for Asian non-Hispanic respondents and those who had older children.

- **Access to Healthcare Services.**

Survey respondents, interviewees and focus group members pointed to the same barriers when accessing healthcare services including finding providers, getting appointments, insurance issues, and cost. Among top difficulties cited by parents/caregivers responding to the community survey were the ability to schedule appointments quickly (52.1%), lack of evening and weekend hours (38.4%), and lack of providers nearby (35.2%). Lack of providers—across the healthcare spectrum but especially among therapies, developmental pediatrics, and dental and mental health—

**Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Healthcare Needs, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

<sup>9</sup> New Jersey Department of Health, 2024.

<sup>10</sup> Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health via New Jersey State Health Assessment Data (NJSHAD), 2024.

<sup>11</sup> New Jersey Department of Health, New Jersey Hospital Discharge Data Collection System, 2025.

was a frequently-mentioned challenge as was the lack of care coordination. Interviewees shared concerns about cuts and potential cuts to public funding that supports special needs children and their families.

- **Use and Perceptions of Telehealth.** Almost 70% of community survey respondents reported that they used telehealth to access medical care for their child with special healthcare needs at least once. The top reason for using telehealth among survey respondents was that it saves time over in-person visits. Those who reported using telehealth largely expressed satisfaction with it.

- **Access to Services that Support Transition to Adulthood**

The process of transitioning from school to adult systems was a frequent topic of conversation in interviews and in the parent focus group, and a prominent theme in the community survey.

Parents/caregivers described challenges planning for transition, including lack of services to assist with this. They also noted a lack of employment and training opportunities

and social and recreational programs for young adults with special healthcare needs.

Numerous survey respondents and focus group participants shared the difficulties of moving their young adult children from pediatric to adult healthcare systems including finding providers in adult healthcare systems who have experience working with special needs patients.

*“Families talk about it: they fall off a cliff. They’re with these pediatric or school systems for a long time. And it’s pretty consistent for the most part, what they’re able to access. And then everything changes over at the same time.”*

– Interviewee

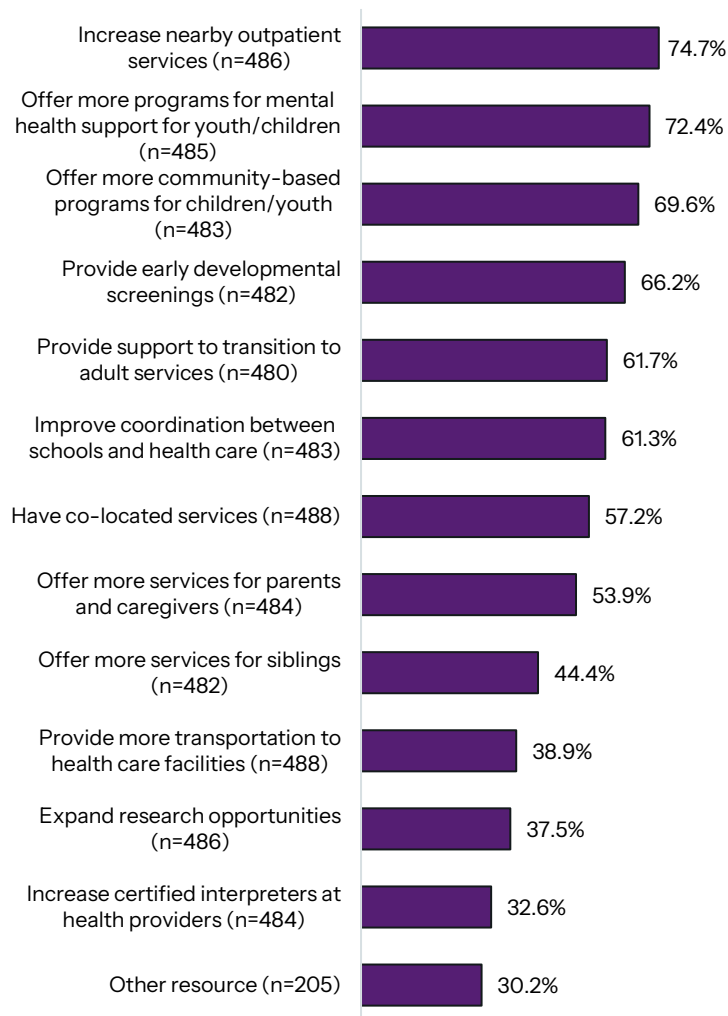
- **Access to Other Services.** Participants and survey respondents reported that New Jersey’s communities have a variety of programs for children and youth with special healthcare needs, including sports and recreation programs for children and support and educational programs for parents/caregivers, yet these are unequally distributed across the state and can be difficult for some families to access. Participants cited barriers such as lack of awareness of available programs and services, need to travel long distances to participate, limited eligibility to “high functioning” children, and cost. Parent and sibling support groups and other programs are also valuable but are not located in all communities. Lack of childcare and language barriers also create barriers to accessing programs to support parents.

### Community Vision and Suggestions for the Future

CSH survey respondents identified outpatient services, mental health programs, community-based programs, and early developmental screenings as highest priority. Survey respondents across all racial and ethnic groups identified mental health programs, community-based programs for children/youth and early developmental screenings among their top five priorities. Increasing nearby outpatient services and more mental health services were identified as among the top five priorities for parents/caregivers of children/youth across all age groups.

- Expanding and Strengthening Healthcare Services.** Focus group participants, interviewees, and survey respondents identified several gaps in healthcare services for children and youth with special healthcare needs. They identified a need for therapists, developmental pediatricians, mental health providers, and dentists, closer to home and willing to accept Medicaid and other insurances. They additionally suggested training and mentoring to enhance the competency and sensitivity of the healthcare workforce. Enhanced coordination between healthcare providers and schools also seen as important.
- Expanding Mental Health Services.** Assessment participants saw a need for more mental health providers, especially those willing to accept Medicaid and other insurances and those who can provide mental health evaluations and have experience working with special needs children and youth.
- Expanding Transition Services.** Parents advocated for more support to help them plan for their children's future, including workshops and presentations. Several participants argued for care coordinators to support the transition to adult services. Because of their role as trusted resources, pediatricians, particularly those in specialty hospitals, were seen as critical in starting these conversations and connecting families to support. Participants advocated for more opportunities that expose young adults with special needs to job and volunteer opportunities during high school and after, as well as more information about post-high school employment, including through opportunities at CSH. Parents/caregivers as well as young adults reported that they would like to see more organizations provide social and recreational opportunities specifically for special needs young adults and ideally, offer transportation so young adults can access them independently.

**Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

- **Increasing Affordable and Accessible Programs for Children and Youth.** CHNA participants recommended more sports programs, summer camps, and afterschool and community programs that offer arts, music, and education. Parents saw a need for free or lower cost programs and those that include children and youth with range of abilities.
- **Expanding Supports for Families.** Supporting families of children with special healthcare needs was a frequent topic of conversation. Parents/caregivers would like more opportunities for education, either in person or virtually. CHNA participants also recommended more programs and groups to help brothers and sisters learn coping skills related to living with a special needs sibling.
- **Focusing on the Social Determinants of Health.** While food needs were not explicitly discussed in interviews or the focus group, participants did note that financial pressures facing some families with special needs children and youth made it more difficult for these families to make ends meet. Transportation is a barrier for some families and suggestions to expand this included more healthcare-sponsored transportation as well as providing gas cards and vouchers for taxis and ride services.

## Key Themes

Several overarching themes emerged from this 2025 assessment.

- ***New Jersey has many assets for children and youth with special healthcare needs and their families; however, there are barriers to accessing these.*** New Jersey has specialty hospitals and other healthcare services, community-based programs that offer sports and socialization opportunities, and statewide organizations that advocate for and educate parents and caregivers. Unequal distribution of these across the state, as well as lack of awareness of them, are barriers to access. Families with special needs children seeking health services face challenges such as too few providers, long wait times for appointments, lack of evening and weekend hours, limits on insurance coverage, and a growing number of providers who do not accept Medicaid. Particularly challenging are finding therapists, developmental pediatricians, and mental health and dental providers. Limited experience among providers working with children and youth with special healthcare needs is also a concern as this negatively affects quality of care and health outcomes. Recreational, sports, and peer socialization programs, as well as programs and support groups for parents and caregivers, are often far from home, have limited enrollments, and are costly.
- ***Increasing access to key health services, including mental health services, is a priority.*** Assessment participants cited a need for more outpatient services such as occupational, physical, and speech therapy, mental health services, and early developmental screenings. Long-term solutions to address workforce are required. More immediately, there may be opportunity to expand access through collaboration with providers elsewhere in the RWJBarnabas Health (RWJBH) system. Addressing the mental health and social emotional needs of special needs children and youth was identified as a high priority by assessment participants. They cited a need for more mental health providers, which they suggested could be addressed in part by enhancing the roles of other professionals, such as nurses and social workers. Expanding the workforce of professionals able to conduct these assessments was also suggested.

- ***Participants see a need for more programs that support preparation for adulthood.***  
Moving from pediatric to adult services is an overwhelming time for parents with special needs children and requires planning and support. Parents/caregivers could benefit from more information and support related to the specific steps they need to take to support their child on the pathway to adulthood. They suggested that pediatric providers could play a role in this. Parents and young adults advocated for more work opportunities and job support, as well as for better incorporation of employment skill building into occupational and speech therapies provided in late adolescence. Increasing recreational and social opportunities as well as leadership skill building for young adults with special needs was also seen as critical to successful adulthood.
- ***Participants would like to see more social and recreational programs for children with special healthcare needs, and support for their parents, caregivers, and siblings.***  
Assessment participants requested more sports programs, summer camps, and afterschool and community programs that offer arts, music, and education to enable special needs children and youth to develop skills and socialize with their peers. Many also noted that parents/caregivers and siblings of children with special healthcare needs could benefit from additional educational and emotional support, including workshops and support groups. Addressing barriers such as transportation, language, and cost is also important.
- ***Addressing social factors that affect health and access to healthcare should be considered.*** Some families experience transportation barriers and food insecurity. Young adults reported that they have difficulty accessing transportation which affects their ability to access employment and education opportunities as well as social and recreational programs. Assessment participants suggested expansion of existing transportation options, especially for medical appointments, through hospital-provided transportation or help with public transportation and car service costs.

## Conclusion

Based on responses gathered from key informant interviews, focus group participants, and community survey respondents, as well as social, economic, and health data from surveillance systems, eight major initial issue areas were identified for the CSH service area:

- Access to adult services
- Access to healthcare services
- Educational access and special education needs
- Financial insecurity
- Food insecurity
- Mental health and social emotional development
- Overweight/obesity
- Transportation

Based on the assessment findings as well as existing initiatives, expertise, capacity, and experience CSH selected the following priorities to focus on when developing their implementation plan: Food Insecurity; Access to Healthcare Services; Transition to Adult Services; and Mental Health and Social Emotional Development.

# Introduction

## **Community Health Needs Assessment Purpose and Goals**

A community health needs assessment (CHNA) is a systematic process to identify and analyze health needs and assets and prioritize those needs to inform the implementation of strategies to improve community health. In 2025, Children's Specialized Hospital undertook a CHNA process using a mixed-methods and participatory approach.

**Children's Specialized Hospital (CSH)** is located in New Brunswick, New Jersey (NJ) and is part of the **RWJBarnabas Health (RWJBH)** system. RWJBH is a non-profit healthcare organization, which includes 12 acute care hospitals, three acute care children's hospitals, a leading pediatric rehabilitation hospital, a freestanding acute behavioral health hospital, a clinically integrated network of ambulatory care centers, two trauma centers, a satellite emergency department, geriatric centers, the state's largest behavioral health network, ambulatory surgery centers, comprehensive home care and hospice programs, fitness and wellness centers, retail pharmacy services, medical groups, diagnostic imaging centers, a clinically integrated network and collaborative accountable care organization.

**Children's Specialized Hospital (CSH)** is the nation's leading provider of inpatient and outpatient care for children from birth to 21 years of age facing special health challenges – from chronic illnesses and complex physical disabilities like brain and spinal cord injuries, to a full scope of developmental, behavioral, and mental health concerns. CSH's purpose is to provide world-leading, family-centered medical and rehabilitative care for children and youth with unique health challenges so every child can reach their full potential. CSH provides services at 14 New Jersey locations, across ten counties, including Atlantic, Essex, Hudson, Mercer, Middlesex, Monmouth, Ocean, Passaic, Somerset, and Union counties. In 2024, CSH cared for over 44,700 children, over 14,000 of whom have autism.

This assessment process builds on previous assessment and planning processes conducted by CSH and its affiliated network. See Appendix G for a description of the hospital's community health activities accomplished and their impact since 2022.

In 2024, RWJBarnabas Health (RWJBH) contracted the services of **Health Resources in Action (HRiA)**, a non-profit public health consultancy organization, to provide support, help facilitate, and conduct data analysis for the CHNA. HRiA worked closely with CSH and the CSH CHNA Advisory Committee to support the CSH CHNA. In addition, RWJBH contracted HRiA to carry out similar assessments across the RWJBH system, to administer a community health survey focused on children with special needs in New Jersey, and to support strategic planning processes for all RWJBH facilities.

The CSH CHNA aims to gain a greater understanding of the issues that residents—particularly children, youth, and young adults with special healthcare needs and their families—face, how those issues are currently being addressed, and where there are gaps and opportunities to address these issues in the future. This report presents findings from the 2025 CSH needs assessment process, which was conducted between January and May 2025.

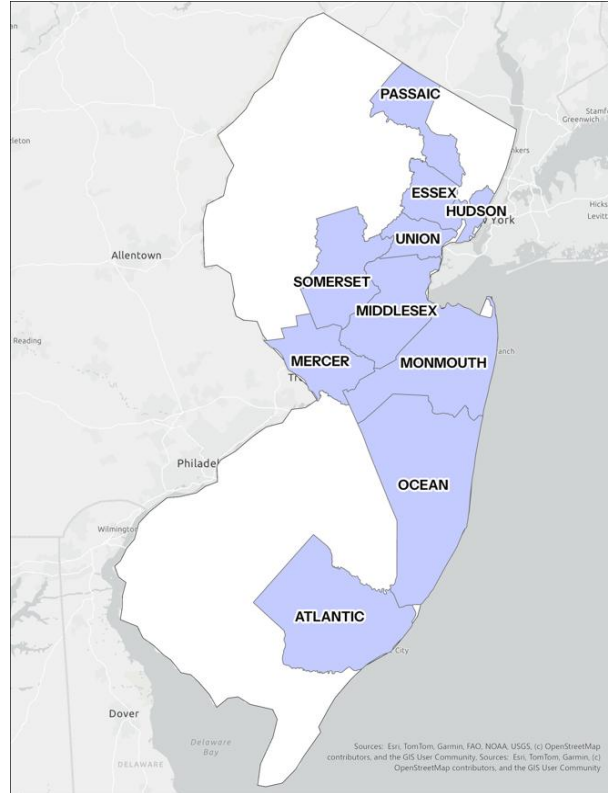
The specific goals of this CHNA are to:

- Systematically identify the needs, strengths, and resources of the community to inform future planning,
- Understand the current health status of children, youth, and young adults with special healthcare needs and their families in the service area overall and its subpopulations within their social context,
- Engage the community to help determine and prioritize community needs and social determinants of health needs, and
- Fulfill the IRS mandate for non-profit hospitals.

### Area of Focus

CSH's focus area is all of New Jersey. Thus, county-level data presented in this CHNA includes all 21 NJ counties; data for the 10 counties with CSH locations are highlighted or, in the case of multi-layered data, asterisked. The CSH CHNA service area is shown in Figure 1. Children's Specialized Hospital CHNA Focus Area Map, 2025.

**Figure 1. Children's Specialized Hospital CHNA Focus Area Map, 2025**



# Methods

The following section describes how data for the CHNA were compiled and analyzed, as well as the broader lens used to guide this process.

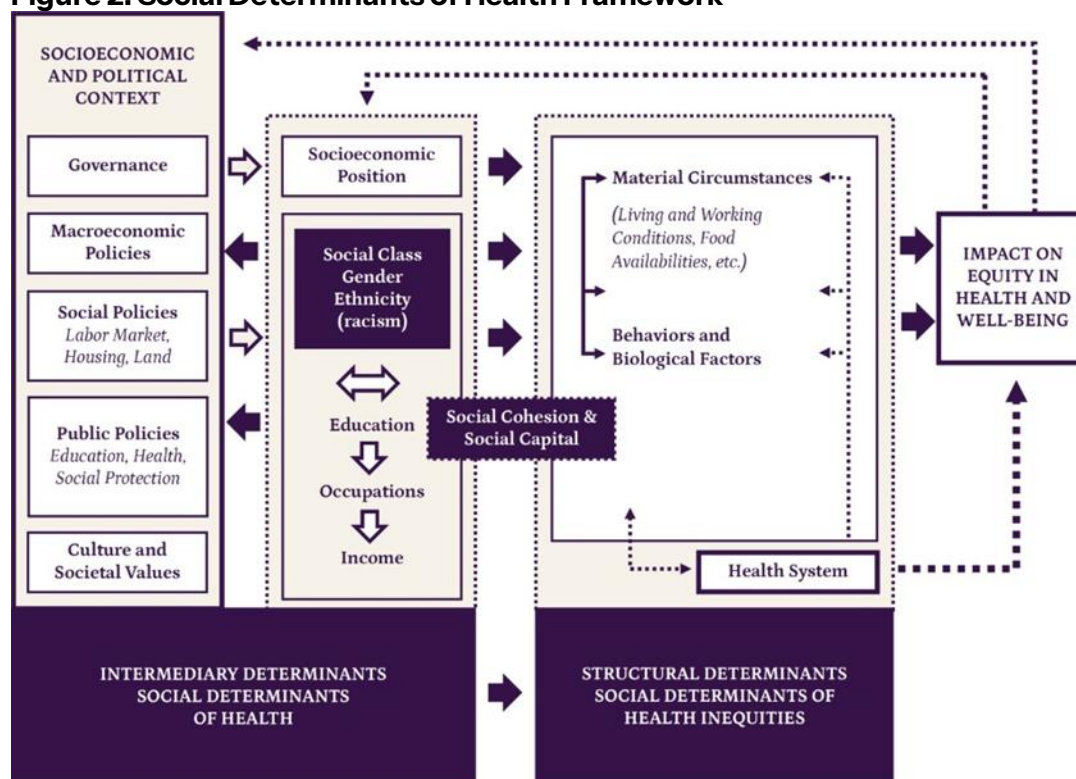
## Social Determinants of Health Framework

While this CHNA aimed to be comprehensive, its data collection approach focused on the social and economic upstream issues that affect a community's health.

### *Upstream Approaches to Health*

Having a healthy population requires more than delivering quality healthcare to residents. Where a person lives, learns, works, and plays has an enormous impact on health. Health is not only affected by people's genes and lifestyle behaviors, the intermediary social determinants of health, but also by upstream factors such as employment status, quality of housing, and economic policies. Figure 2 provides a visual representation of these relationships, depicting how individual lifestyle factors are influenced by structural social determinants of health, that shape a person's access to educational opportunities and income, which in turn are influenced by the socioeconomic and political context. Further, the health system moderates the relationship between the material and biopsychosocial factors and health and well-being.

**Figure 2. Social Determinants of Health Framework**



DATA SOURCE: World Health Organization, Commission on the Social Determinants of Health, A Conceptual Framework for Action on the Social Determinants of Health, 2010.

In addition, healthcare insurers, regulators, and providers have recognized health-related social needs as those social factors that directly impact the health of individuals, such as economic strain and food availability. Healthcare sector partners can take steps to address and mitigate the impact of the health-related social factors on health through screening and referrals to social and community-based services.<sup>12</sup>

The data to which we have access is often a snapshot in time, but the people represented by that data have lived their lives in ways that are constrained and enabled by economic circumstances, social context, and government policies. To this end, this report discusses the social, economic, and community context in which residents live.

### *Health Equity Lens*

The influences of race, ethnicity, income, and geography on health patterns are often intertwined. In the United States, social, economic, and political processes ascribe social status based on race and ethnicity, which may influence opportunities for educational and occupational advancement and housing options, two factors that profoundly affect health. Institutional racism, economic inequality, discriminatory policies, and historical oppression of specific groups are a few of the factors that drive health inequities.

The present report describes health patterns for the New Jersey population overall, as well as areas of need for specific subpopulations. Understanding factors that contribute to health patterns for these groups can facilitate the identification of data-informed and evidence-based strategies to provide all residents with the opportunity to thrive and live a healthy life.

### **Approach and Community Engagement Process**

The CHNA aimed to engage a broad range of stakeholders that contribute to residents' health, including health departments, hospitals, community-based organizations, academic partners, and community residents through different avenues. The CHNA process was guided by strategic leadership from the RWJBH Systemwide CHNA Steering Committee, the CSH CHNA Advisory Committee, and the community overall.

### *Advisory Committee Engagement*

The CSH CHNA Advisory Committee was engaged throughout this process. The Committee met virtually in February 2025 to launch the CHNA process and provided ongoing feedback over email on CHNA methodology, the community survey, local data sources, survey administration methods, and priority stakeholders and population groups to engage in discussions. Committee members provided outreach support for HRiA to connect with stakeholders and specific population groups. The Committee also utilized the CHNA data to inform community health priorities. Community members with specialized knowledge of underrepresented populations were intentionally included in the process. Additionally, the Committee members participated in a community prioritization meeting (see below for more information).

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<sup>12</sup> Centers for Medicare & Medicaid Services, Social Drivers of Health and Health-Related Social Needs, 2024

### *Community Engagement*

Community engagement is described below under the primary data collection methods. Capturing and lifting up a range of voices, especially those not typically represented in these processes, was a core component of this initiative. Community engagement was done via virtual focus groups and surveys, both online and in person. By engaging the community through multiple methods, this CHNA aimed to depict a full and multifaced picture of current community strengths and needs.

### **Secondary Data: Review of Existing Data, Reports, and Analyses**

Secondary data are data that have already been collected for other purposes. Examining secondary data helps us to understand trends and identify differences by sub-groups. It also helps guide where primary data collection can dive deeper or fill in gaps.

Secondary data for this assessment were drawn from a variety of national, state, and local sources, including the U.S. Census American Community Survey (ACS), the National Survey of Children's Health, the New Jersey Department of Education, the New Jersey Department of Health, the New Jersey Department of Health's New Jersey State Health Assessment Data (NJSHAD), the New Jersey Division of Developmental Disability, and a number of other agencies and organizations.

Secondary data were analyzed by the agencies that collected or received the data. Data were downloaded from the respective websites between January and March, 2025, and reflect the last year for which data were available at that time. Data are typically presented as frequencies (%) or rates per 100,000 population. The race and ethnicity categories used in this report are as reported by the respective agencies. When the narrative makes comparisons between towns, by subpopulation, or with New Jersey overall, these are lay comparisons and *not* statistically significant differences. Sometimes, reporting agencies do not provide certain data points. This could be due to several reasons: the agency might not have the statistics, they might have suppressed the data because of low numbers, or the data might not have met statistical reliability standards. In any of these cases, we placed an asterisk (\*) to indicate data were not available.

In addition to data from surveillance systems, this report also contains social determinants of health data collected through a screening survey of CSH outpatient medical, long-term care, and therapy patients (physical therapy, occupational therapy, and speech, with additional therapy patients to be reached in the future). The survey collects data about transportation, housing, and food insecurity status. Data shared in this report come from screening data collected between January and September 2024, during which time 17,048 screenings were conducted, across all CSH sites.

This 2025 CSH CHNA focuses on all of New Jersey's 21 counties that are part of CSH's primary service area. Data for the 10 counties with CSH locations are highlighted or, in the case of multi-layered data, asterisked.

## Primary Data Collection

### Qualitative Discussion: Key Informant Interviews and Focus Groups

#### *Key Informant Interviews*

Between April and May, 2025, a total of eight key informant interview discussions were completed with ten individuals by Zoom. Interviews were 45–60-minute semi-structured discussions that engaged institutional, organizational, and community leaders as well as front-line staff across sectors. Discussions explored interviewees’ experiences of addressing community needs and priorities for future alignment, coordination, and expansion of services, initiatives, and policies. Sectors represented in these interviews included: public health, adult services, advocacy, public education and community-based services. See Appendix A for the list of organizations engaged through key informant interviews and Appendix B for the key informant interview guide.

#### *Focus Group*

One 90-minute virtual focus group was held with parents/caregivers who participate in CSH’s Family Advisory Council and CSH’s Family Faculty and their young adult children in April, 2025. A total of nine individuals participated. The semi-structured conversation aimed to delve deeply into the needs, strengths, and opportunities for the future for children with special healthcare needs and their families and to gather feedback on priorities for action. See Appendix C for the focus group facilitator’s guide.

#### *Analyses*

The collected qualitative information was coded and then analyzed thematically by HRiA data analysts to identify main categories and sub-themes. The analysts identified key themes that emerged across all groups and interviews as well as the unique issues that were noted for specific populations. Throughout the qualitative findings included in this report, the term “participants” is used to refer to key informant interview and focus group participants. Unique issues that emerged among a group of participants are specified as such. The frequency and intensity of discussions on a specific topic were the key indicators used for extracting the main themes. While differences between towns are noted where appropriate, analyses emphasized findings common across the focus area. Selected paraphrased quotes—without personal identifying information—are presented in the narrative of this report to further illustrate points within topic areas.

### Community Survey Focused on Children with Special Healthcare Needs

A community survey was administered online in English and Spanish to parents/caregivers of children, young adults with special healthcare needs, as well as other family members and those who work with these children and youth. The survey instrument was adapted from a similar survey conducted for the CSH CHNA in 2022. The survey was fielded over a four-week period from mid-March to mid-April 2025. Survey questions focused on: accessibility of services and programs for children with special healthcare needs and their families; challenges accessing healthcare and other services and programs; needed services and programs; food security, and telehealth utilization. Extensive outreach was conducted by CSH, CSH CHNA Advisory Committee members, and partners. Flyers with a survey QR code were displayed at CSH and partner sites.

The final sample of the community survey analyzed in this report included 637 respondents: 578 parents/caregivers and 59 others who engage with children with special healthcare needs. Appendix E provides the sociodemographic characteristics of these survey respondents. In addition, five young adults with special healthcare needs responded to the survey. Data from these survey respondents are discussed thematically rather than visualized due to the low response rate of this specific population. Throughout this report, people who completed the survey are referred to as “respondents” (whereas those who were part of focus groups and interviews are referred to as “participants” for distinction).

### *Analyses*

Frequencies were calculated for each survey question. Not all respondents answered every question; therefore, denominators in analyses reflect the number of total responses for each question, which varied by question. Survey data presents race and ethnicity categories as selected by respondents. The race and ethnicity categories were asked in a multiple-choice question that allows for several answers. To recognize respondents’ multiple identities, the race and ethnicity categories are presented alone or in combination. For example, if someone selected “Asian” and “Black or African American” they would appear in both categories. Thus, as with other multiple-choice questions that allow for multiple responses, the percentages may not add to 100 percent. Statistical testing was not conducted on these results and, thus, any differences discussed across respondents are descriptive only.

### *Data Limitations*

As with all data collection efforts, several limitations should be acknowledged. Numerous secondary data sources were drawn upon in creating this report and each source has its own set of limitations. Overall, it should be noted that different data sources use different ways of measuring similar variables (e.g., different questions to identify race and ethnicity). There may be a time lag for many data sources from the time of data collection to data availability. Some data are not available by specific population groups (e.g., age) or at a more granular geographic level (e.g., town or municipality) due to small sub-sample sizes. In some cases, data from multiple years may have been aggregated to allow for data estimates at a more granular level or among specific groups.

The CSH community health survey used a convenience sample. Since a convenience sample is a type of non-probability sampling strategy, there is potential selection bias in who participated or was asked to participate in the survey. Due to this potential bias and that data are reported unweighted, results cannot necessarily be generalized to the larger population. However, a range of strategies such as dissemination by partners, multiple collection sites, access points, and survey administration modalities were used to minimize selection bias.

Similarly, while interviews and focus groups provide valuable insights and important in-depth context, due to their non-random sampling methods and small sample sizes, results are not necessarily generalizable. This report should be considered a snapshot of the current time. The findings in this report can be built upon through future data collection efforts.

### *Context for Comparisons to Previous CHNA*

As appropriate, comparisons are made throughout this report between the previous and the current assessment. It is important to keep in mind that these comparisons may not be as relevant given that the previous CHNA was conducted during the height of the COVID-19

pandemic and that this CHNA was conducted in 2025 during a period of transition in the federal government. Changes in leadership at the national level can reshape policy priorities, funding streams, and regulatory frameworks — factors that directly affect residents' health and well-being and local organizations' capacity to serve them. As federal policies continue to evolve, it remains essential to continue to understand the assets, challenges, and priorities of diverse communities, especially those with a higher burden of health inequities. Of note, in times of change, assessing the community's resilience and strengths is critically important.

# Population Characteristics

## Population Overview

According to the 2019–2023 American Community Survey (U.S. Census), the total population of New Jersey is slightly over nine million (Table 1). While Children’s Specialized Hospital (CSH) serves children and families throughout New Jersey, its sites are located in ten counties. The counties served by CSH sites (which are in purple) range in population size, from 274,704 in Atlantic County to 861,535 in Middlesex County.

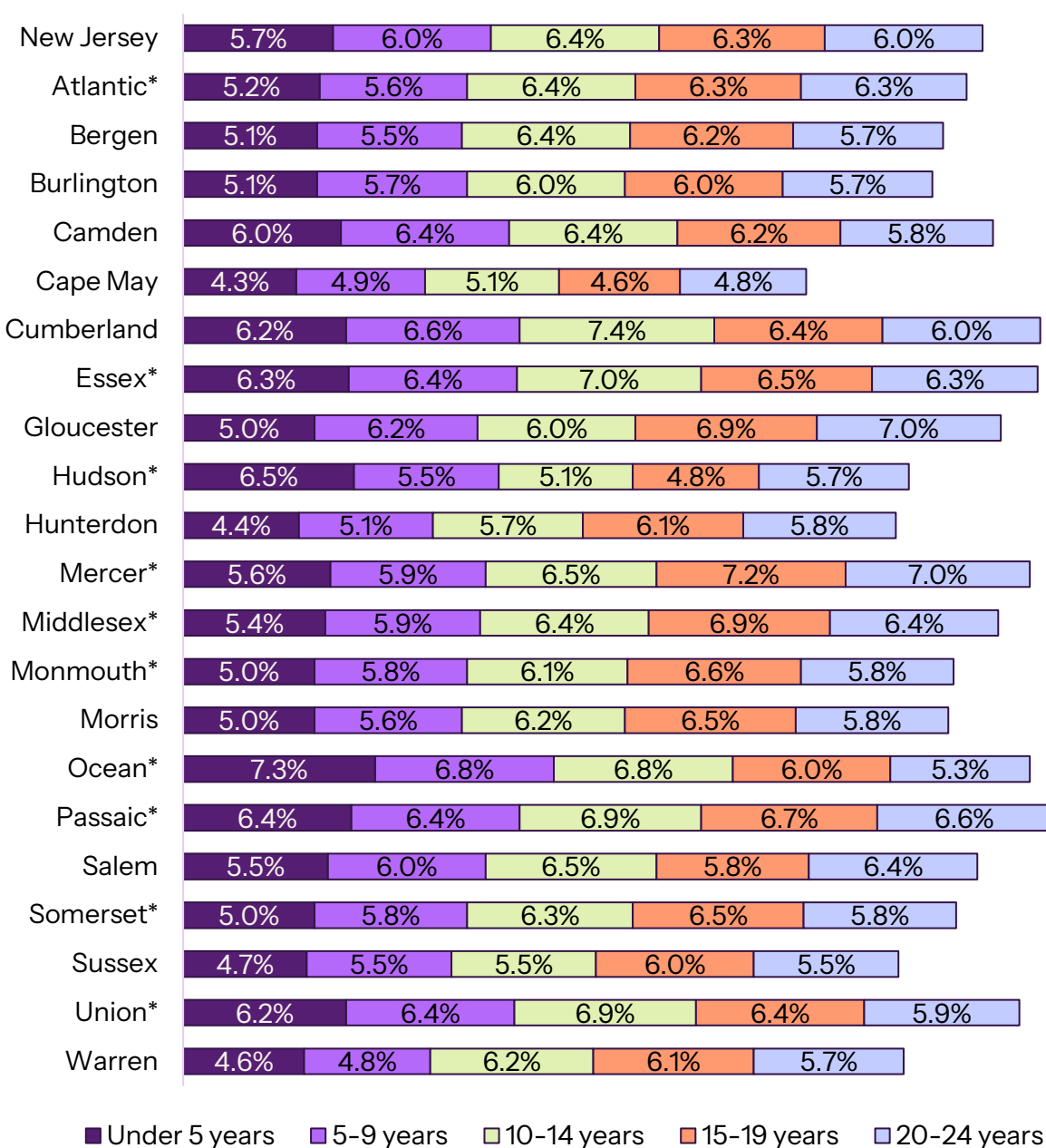
**Table 1. Total Population, by State and County, 2019–2023**

	2019–2023
New Jersey	9,267,014
Atlantic	274,704
Bergen	954,717
Burlington	464,226
Camden	524,042
Cape May	95,236
Cumberland	152,915
Essex	854,130
Gloucester	304,504
Hudson	710,478
Hunterdon	129,448
Mercer	383,286
Middlesex	861,535
Monmouth	643,615
Morris	510,375
Ocean	646,434
Passaic	518,289
Salem	64,973
Somerset	346,203
Sussex	145,117
Union	572,549
Warren	110,238

DATA SOURCE: U.S. Census Bureau, American Community Survey 5–Year Estimates, 2019–2023

About 30% of New Jersey’s population is under age 24 (Figure 3). Among counties with CSH locations, the proportion of residents under age 24 ranges from 27.6% in Hudson to 33.0% in Passaic. Among counties with CSH locations, Ocean County (7.3%) has the highest proportion of residents under age 5. Mercer (7.0%) has the highest proportion of residents between the ages of 20–24. Passaic (20.0%), Essex (19.9%), Union (19.7%), Mercer (19.6%), and Ocean (19.6%) counties have the highest proportion of school-age children (ages 5–19).

**Figure 3. Total Population Under 24 by Age Group, by State and County, 2019–2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019–2023

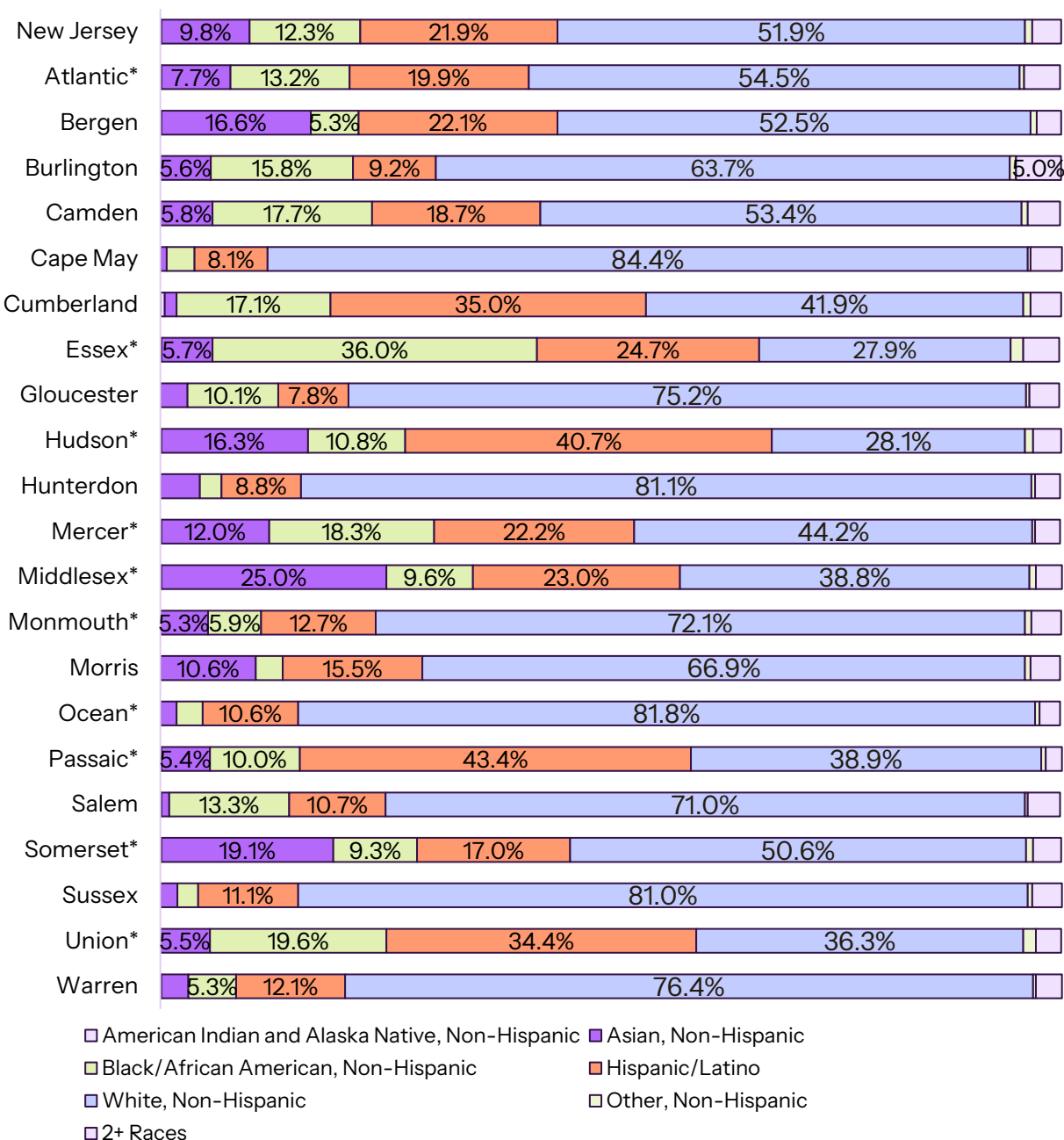
## Racial, Ethnic, and Language Diversity

### Racial and Ethnic Composition

2019–2023 American Community Survey data about the racial and ethnic distribution of New Jersey as a whole and by county are shown in Figure 4. About half of New Jersey residents self-identify as non-Hispanic White (51.9%), followed by residents who self-identify as Hispanic (21.9%) and non-Hispanic Black (12.3%). CSH has locations in some of New Jersey’s most racially and ethnically diverse counties. Among the ten counties in which CSH facilities

are located (which have an asterisk in the graph), Passaic County has the highest percentage of residents who self-identify as Hispanic/Latino (43.4%); Essex County has the highest percentage of residents who self-identify as non-Hispanic Black (36.0%); and Middlesex County has the highest percentage of non-Hispanic Asian residents (25.0%). Ocean County has the highest percentage of residents who self-identify as non-Hispanic White (81.8%).

**Figure 4. Total Population, by Race/Ethnicity, by State and County, 2019-2023**



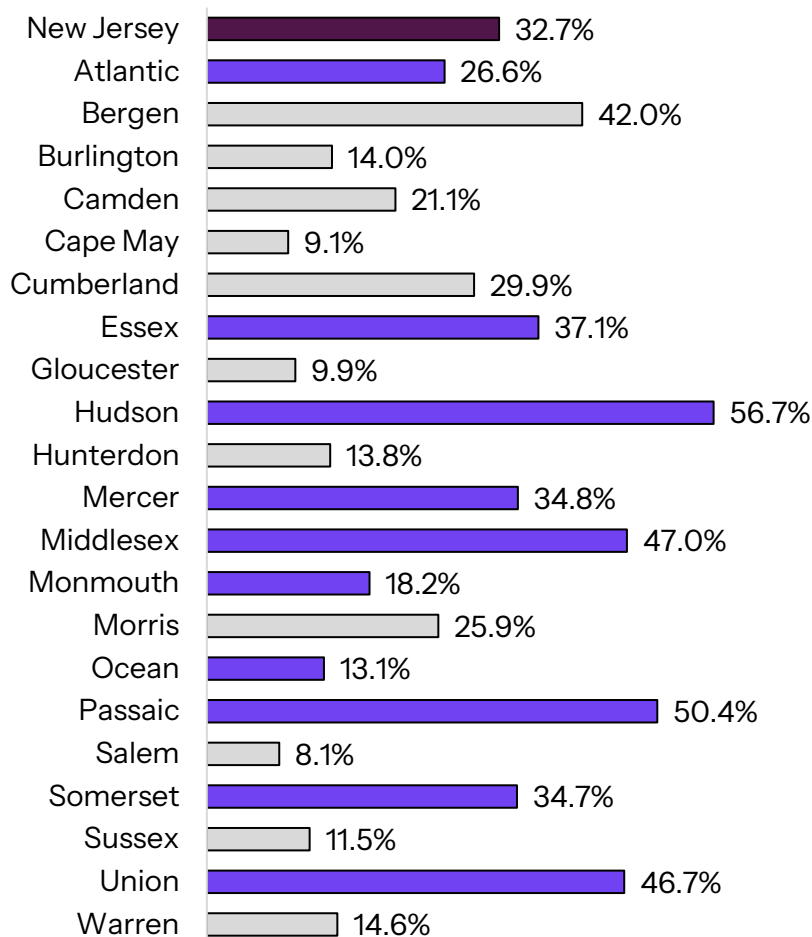
DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

NOTE: Data labels under 5.0% are omitted from the graphic.

### Language Diversity

Figure 5 presents data from the American Community Survey about the proportion of residents who speak a language other than English at home. Over 30% of New Jersey residents speak a language other than English at home. Among the ten counties in which CSH facilities are located (in the purple bars), the proportion of the population speaking a language other than English at home ranges from 13.1% in Ocean County to 56.7% in Hudson County. In seven (Essex, Hudson, Mercer, Middlesex, Passaic, Somerset, and Union) of the counties with CSH locations, the proportion of the population who speaks a language other than English at home is higher than the state.

**Figure 5. Percent Aged 5+ Who Speak a Language Other than English at Home, by State and County, 2019- 2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

About 17% of New Jersey's residents speak Spanish at home (Table 2). CSH has locations in the three New Jersey counties with the highest proportion of residents who speak Spanish at home: Hudson (33.8%), Passaic (36.7%), and Union (29.6%). CSH is also located in counties with a high proportion of Chinese speakers (Somerset), other Asian language speakers (Middlesex), and other Indo-European language speakers (Middlesex). Interviewees and

survey respondents cited language barriers as a challenge some families face when accessing healthcare and other services for special needs children. While interpretation services exist at CSH and many providers' offices, respondents reported that they are not as readily available for specialty services such as therapies or mental health. Additionally, language barriers can make it challenging for some families to access information about services and complete paperwork needed to access support from Medicaid, the Division of Vocational Rehabilitative Services (DVRS) and other state systems.

**Table 2. Top 5 Non-English Languages Spoken at Home, by State and County, 2019-2023**

	Spanish	Other Indo-European Languages	Russian, Polish, or other Slavic Languages	Other Asian and Pacific Island languages	Chinese (including Mandarin Chinese)
New Jersey	17.0%	5.5%	1.7%	1.6%	1.4%
Atlantic	15.2%	4.3%	1.1%	0.5%	1.3%
Bergen	16.9%	5.6%	4.2%	2.3%	2.4%
Burlington	5.0%	3.0%	0.8%	1.7%	0.7%
Camden	13.0%	2.2%	0.8%	0.8%	0.9%
Cape May	5.3%	1.5%	1.0%	0.2%	0.1%
Cumberland	26.0%	1.4%	1.1%	0.4%	3.0%
Essex	19.9%	5.9%	1.0%	0.8%	1.1%
Gloucester	5.0%	1.9%	0.5%	0.5%	0.2%
Hudson	33.8%	8.2%	2.0%	1.9%	2.7%
Hunterdon	5.3%	3.4%	1.4%	0.9%	0.6%
Mercer	18.6%	5.3%	1.8%	2.6%	2.1%
Middlesex	18.3%	12.5%	2.1%	4.9%	2.7%
Monmouth	7.7%	4.0%	1.8%	0.6%	1.4%
Morris	11.7%	5.6%	1.8%	2.0%	2.1%
Ocean	6.0%	1.6%	0.9%	0.2%	0.3%
Passaic	36.7%	4.8%	2.4%	1.1%	0.5%
Salem	5.8%	1.0%	0.2%	0.0%	0.1%
Somerset	13.1%	8.5%	1.8%	3.1%	3.7%
Sussex	6.2%	1.6%	1.5%	0.4%	0.3%
Union	29.6%	6.5%	1.9%	0.6%	1.3%
Warren	7.7%	2.3%	1.3%	0.3%	0.5%

DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

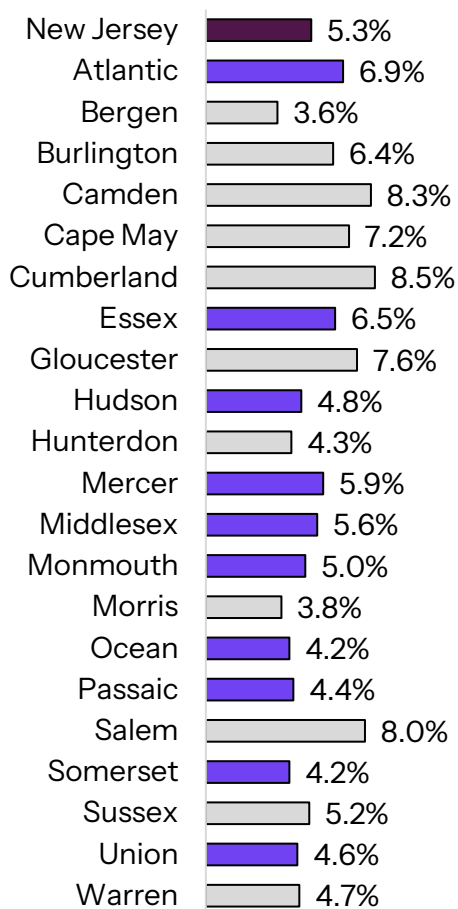
### Population of Children with Special Healthcare Needs in New Jersey

CSH provides inpatient and outpatient care for children with special healthcare needs throughout New Jersey. This section shares available secondary data about children and youth with special healthcare needs. The data in this section come from a variety of sources; in some cases, these data are available at the county level; in others, they are only available for the state of New Jersey.

According to the 2019-2023 American Community Survey, 5.3% of New Jersey's population under age 18 has a disability, defined as having a hearing, vision, cognitive, ambulatory, self-

care, or independent living difficulty (Figure 6). Across counties with CSH locations, the proportion of children under age 18 with a disability ranges from 4.2% in Ocean and Somerset to 6.9% in Atlantic.

**Figure 6. Percent Population Under 18 Years with a Disability, by State and County, 2019-2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

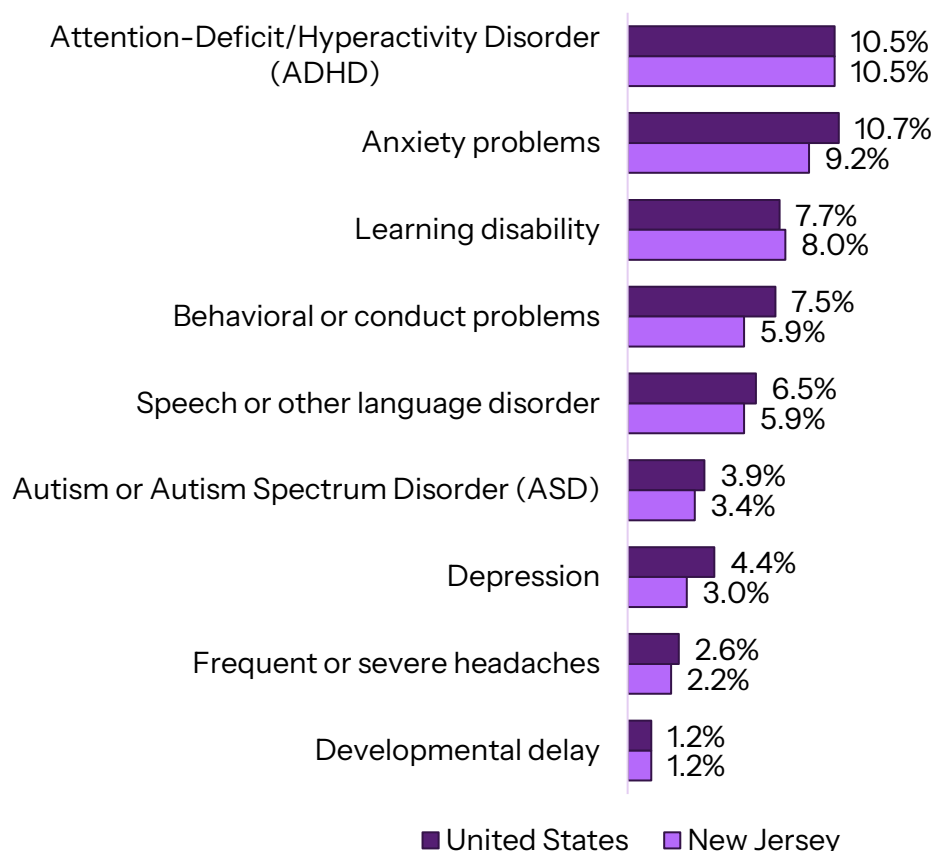
The National Survey of Children's Health (NSCH) collects information specifically about children and youth with special healthcare needs; these data are only available at the national and state levels. NSCH defines Children and Youth with Special Healthcare Needs (CYSHCN) as children under age 18 "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."<sup>13</sup>

According to the 2022-2023 NSCH survey, 20.8% of children under age 18 nationally and 19.9% of children under age 18 in New Jersey met this definition of having special healthcare needs. Data from the NSCH about specific diagnoses related to special needs are presented

<sup>13</sup> <https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nhsc-data-brief-children-youth-special-health-care-needs.pdf>

in Figure 7. These data indicate that the proportions of children ages 3-17 with a disability is the same or slightly lower in New Jersey than nationwide for all conditions except learning disabilities, where the proportion of children with this diagnosis is slightly higher in New Jersey (8.0%) than in the U.S. overall (7.7%). Within New Jersey, the highest proportion of children with diagnosed disabilities have ADHD (10.5%), anxiety problems (9.2%), and learning disabilities (8.0%).

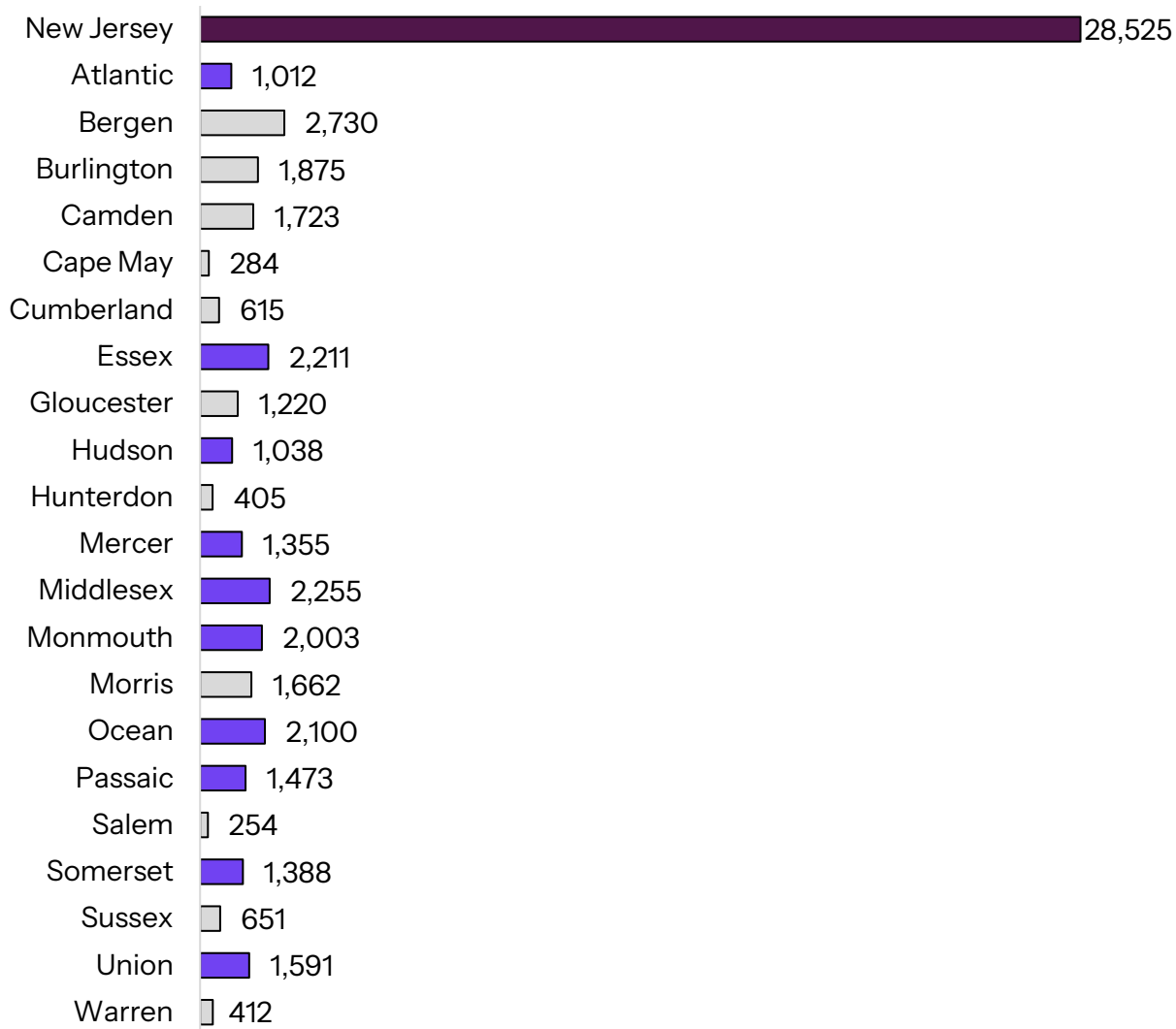
**Figure 7. Percent Children Aged 3-17 Years with Current or Lifelong Condition, by U.S. and State, 2022-2023**



DATA SOURCE: National Survey of Children's Health, 2022-2023

Recent data from the New Jersey Division of Developmental Disability indicate that as of the end of 2024, 28,525 individuals ages 10 and older from the state of New Jersey were receiving services from the NJ Division of Developmental Disabilities (Figure 8). A total of 16,426 individuals ages 10 and older were receiving services from the Division in the ten counties where CSH has sites.

**Figure 8. Number of People Receiving Services Funded by the New Jersey Department of Human Services, Division of Developmental Disability, by County, 2024**

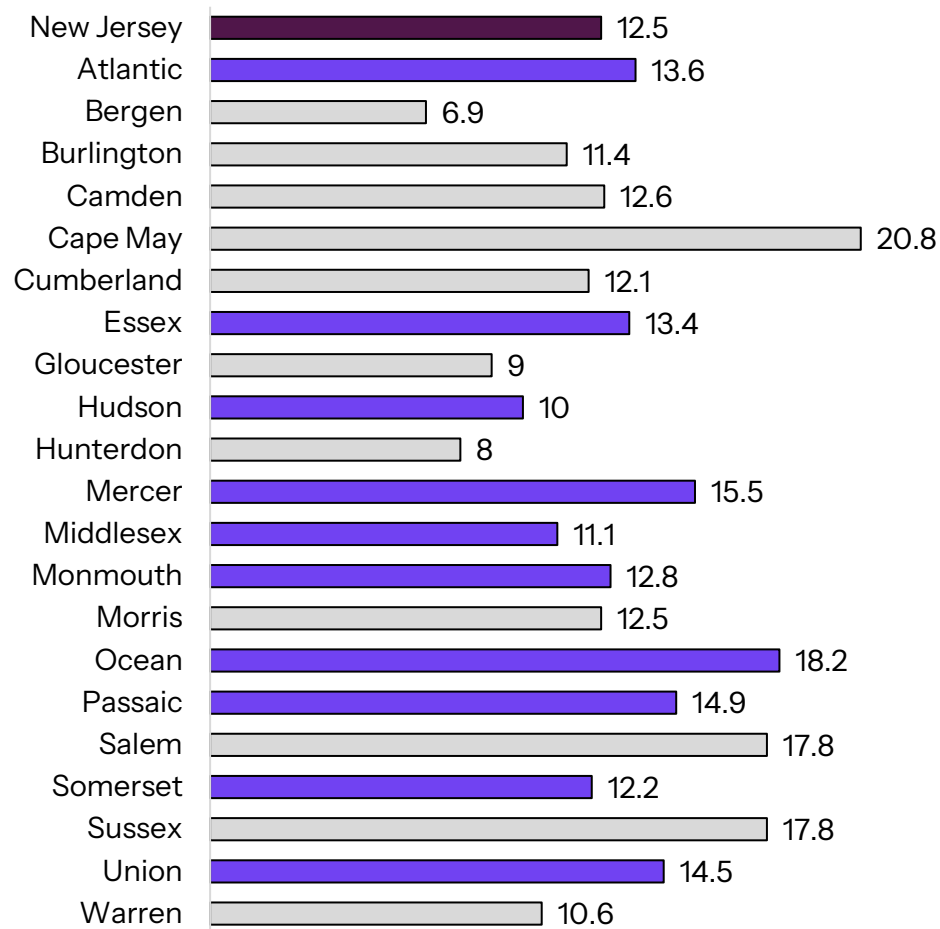


DATA SOURCE: New Jersey Department of Human Services, Division of Developmental Disabilities, 2024

Birth defects are structural, functional and metabolic abnormalities present at birth and result in physical and mental disability. According to CDC, babies born with birth defects have greater chance of illness and long-term disability and often need special care and interventions to survive and to thrive developmentally.

Data from the Birth Defects Registry of New Jersey for the period 2017–2021 shows 12.5 cases of chromosomal abnormalities per 10,000 births statewide (Figure 9). Of the ten counties in which CSH facilities are located, seven (Atlantic, Essex, Mercer, Monmouth, Ocean, Passaic, and Union) had higher rates of chromosomal birth defects than the state. Ocean County had the highest prevalence of chromosomal birth defects (18.2 per 10,000 births) among counties with CSH locations.

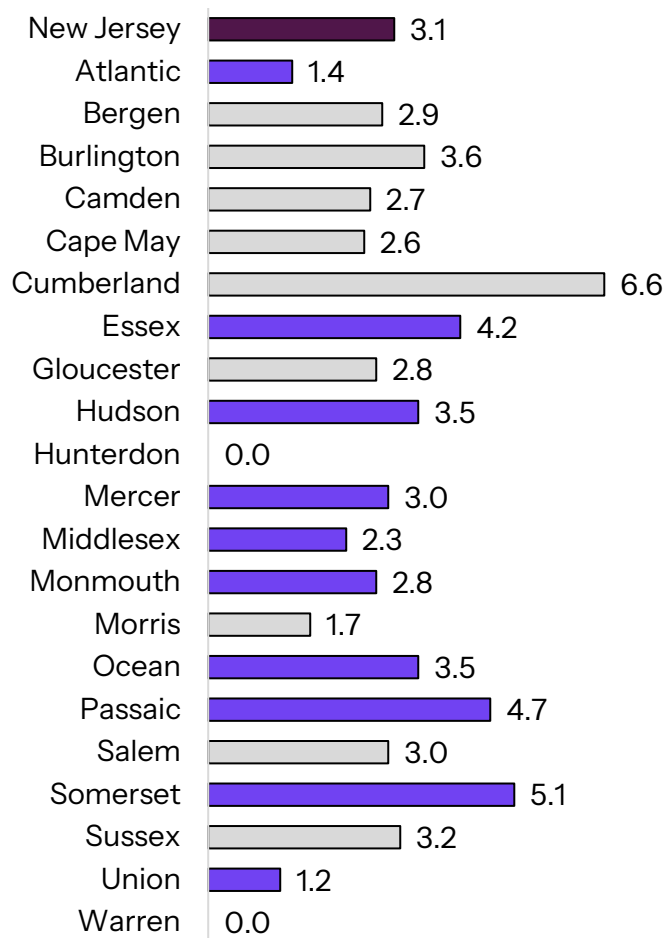
**Figure 9. Prevalence of Chromosomal Birth Defects per 10,000 Births, by State and County, 2017–2021**



DATA SOURCE: NJ Birth Defects Registry, New Jersey Department of Health County Profiles, 2017–2021

The prevalence of Central Nervous System (CNS) birth defects was higher in five CSH Counties (Essex, Hudson, Ocean, Passaic, and Somerset) as compared to statewide prevalence (3.1 per 10,000 births) (Figure 10). Somerset County had the highest prevalence of CNS birth defects (5.1 per 10,000 births) among counties with CSH locations.

**Figure 10. Prevalence of Central Nervous System (CNS) Birth Defects per 10,000 Births, by State and County, 2017-2021**



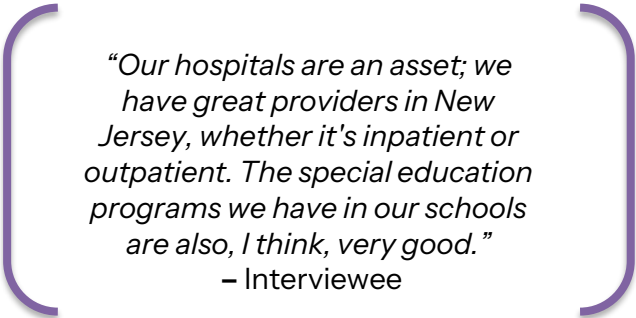
DATA SOURCE: NJ Birth Defects Registry, New Jersey Department of Health County Profiles, 2017-2021

# Community Social and Economic Environment

Income, work, education, and other social and economic factors are powerful social determinants of health. For example, jobs that pay a living wage enable workers to live in neighborhoods that promote health (e.g., built environments that facilitate physical activity, resident engagement, and access to healthy foods), and provide income and benefits to access healthcare. In contrast, unemployment, underemployment, and job instability make it difficult to afford housing, goods, and services linked with health and healthcare access, and contribute to stressful life events that affect multiple aspects of health.

## Community Strengths and Assets

Understanding the resources and services available in a community—as well as their geographic distribution—helps to identify the assets that can be drawn upon to address community health, as well as any gaps that might exist. Interviewees and survey respondents shared that New Jersey has many resources to support children with special healthcare needs and their families. There are numerous healthcare services: in addition to CSH, community survey respondents reported that their children receive services from Bristol-Myers Squibb Children’s Hospital at Robert Wood Johnson University Hospital, Nemours Children’s Health, Shriner’s Hospital, and Goryeb Children’s Hospital, among others. In addition, New Jersey has four long-term care facilities for children/youth, including two operated by CSH.



*“Our hospitals are an asset; we have great providers in New Jersey, whether it’s inpatient or outpatient. The special education programs we have in our schools are also, I think, very good.”*

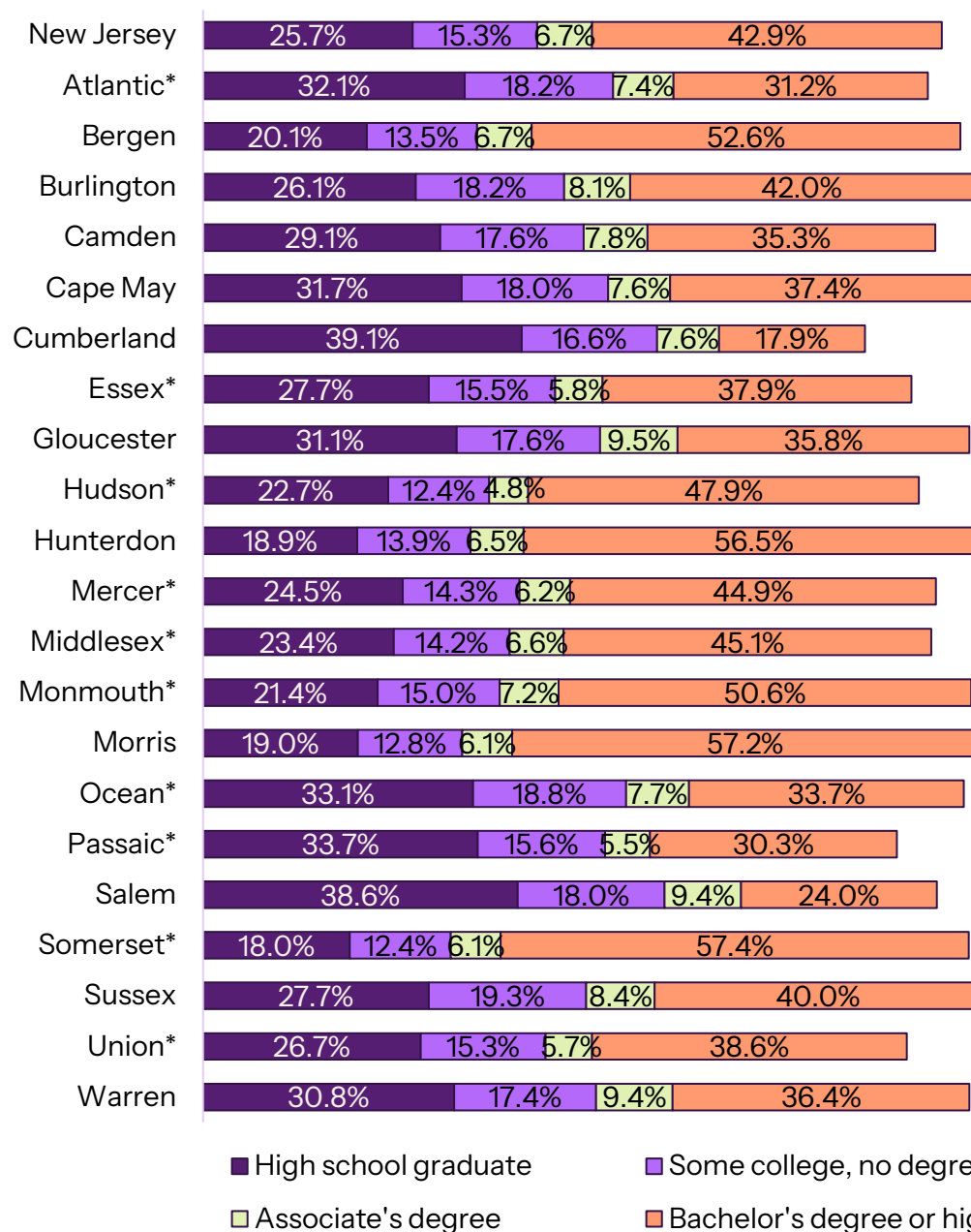
– Interviewee

Participants mentioned the role of SPAN Parent Advocacy Network, the Arc of New Jersey, school district-based Special Education Parent Advisory Groups (SEPAG), and the Boggs Center on Developmental Disabilities at Rutgers in providing information, educational opportunities and advocacy to families with special needs children. Parents also shared that they received support from Perform Care, New Jersey’s Children’s System of Care Administrator, as well as from county-based programs supported by federal Title V funding. Families of older youth stated that their children are able to access employment, educational, and everyday living support through programs offered by the Division of Vocational Rehabilitative Services (DVRS) and the Intellectual and Developmental Disabilities (IDD) program. Participants also mentioned several sports and recreational programs for special needs children and youth including Special Olympics, community recreation departments and 4H, Buddy Baseball, Spectrum Stars, RallyCap Sports, Boy Scouts, camps such as Camp Chatterbox and Camp Fatima, and RWJBarnabas Health’s Field of Dreams sports complex.

## Education

Educational attainment is an important measure of socioeconomic position that may reveal additional nuances about populations, in addition to measures of income, wealth, and poverty. As shown in Figure 11, 42.9% of adults age 25 years and old in New Jersey have obtained at least a Bachelor's degree. Among the counties in which CSH is located, the percentage of adults with a Bachelor's degree or higher is lower in Atlantic, Essex, Ocean, Passaic, and Union than in New Jersey overall.

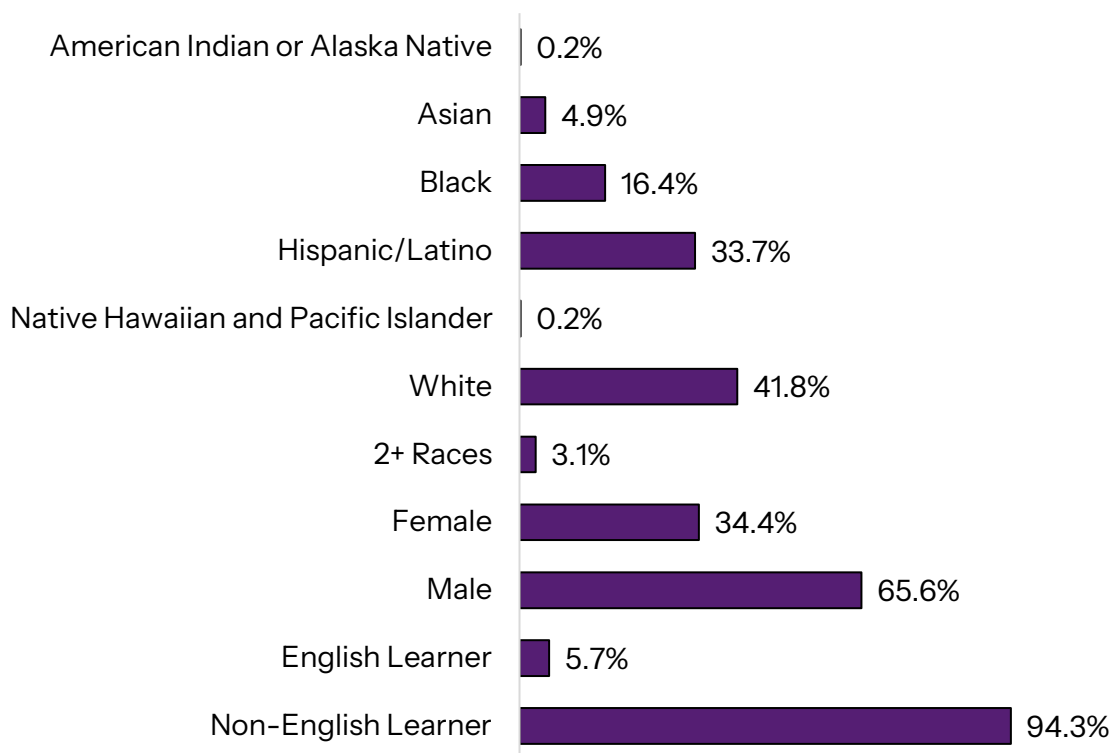
**Figure 11. Educational Attainment Among Adults Aged 25+, by State and County, 2019-2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

Special education data from the NJ Department of Education show that 225,333 students ages 6 to 21 received special education services in New Jersey; viewed proportionally, a higher percentage of students ages 6 to 21 received special education services in New Jersey (12.2%) compared to the U.S. overall (10.1%).<sup>14</sup> About 40% of students ages 3–21 receiving special education services in New Jersey in 2023–2024 were White, 66% were male, and 94% were non-English learners (Figure 12). Among New Jersey students ages 3–21 with special needs, about 30% had a specific learning disability, 22% had a speech or language impairment, and 20% had another health impairment, as shown in the figure on the subsequent page. In 2023–2024, about 13% of students receiving special education services had autism.

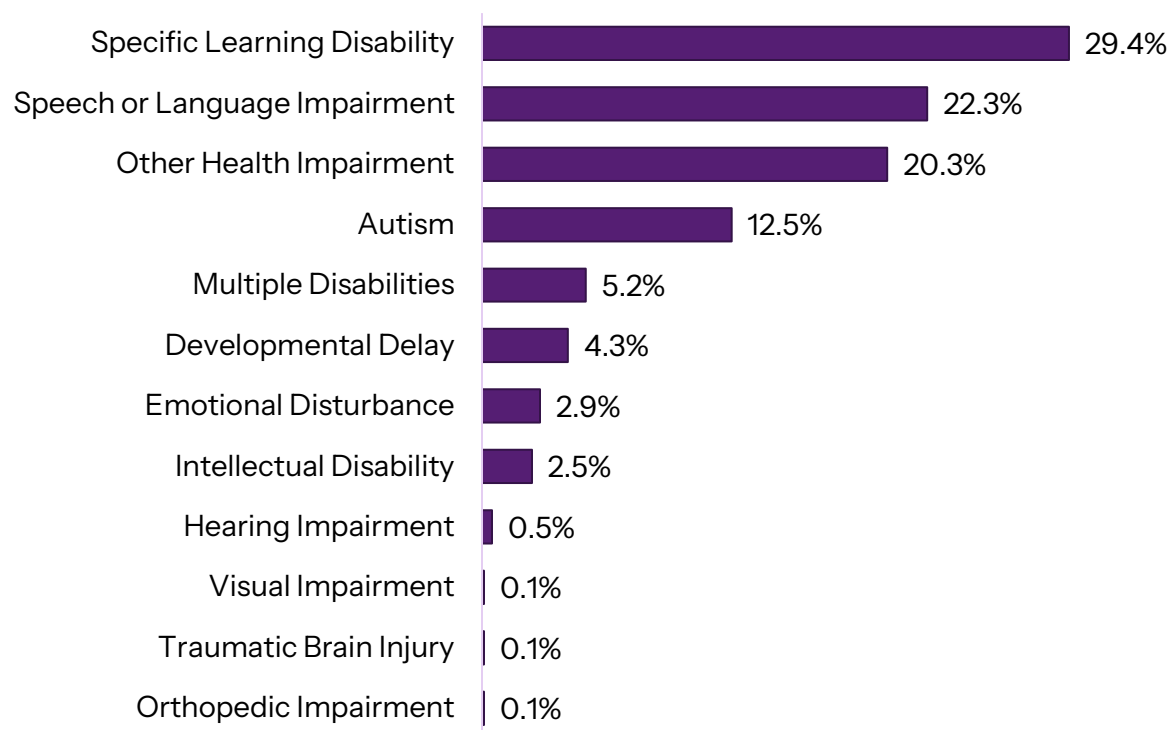
**Figure 12. Percent Special Education Students Aged 3–21, by Race/Ethnicity, Gender, and English Learner Status, 2023–2024**



DATA SOURCE: New Jersey Department of Education, 2023–2024

<sup>14</sup> DATA SOURCE: Thomas, N., Paul, S., Bach, S., & Houtenville, A. (Eds.) (2024). Annual Disability Statistics Compendium: 2024 (Table 13.1). Durham, NH: University of New Hampshire, Institute on Disability.

**Figure 13. Percent Special Education Students Aged 3-21, by Disability, 2023-2024**



DATA SOURCE: New Jersey Department of Education, 2023-2024

Schools play an important role in supporting children with special needs. Special education services are outlined in Individualized Education Plans (IEPs) and 504 Plans that identify students' educational needs and goals and are developed through a collaborative process with parents, teachers, and other professionals. In addition to education,

*"We don't have the educators. We don't have the related service professionals. We surely don't have the aides, and we don't have the money."*

– Interviewee

school districts provide a variety of services, including occupational (OT), physical (PT), and speech therapy, to students who need this support. In January 2024, CSH began providing school-based evaluations, consultations, and direct OT, PT, and speech services for preschool through high school age students in eight New Jersey counties through its School Services Program (formerly Trinitas Children's Therapy Services).

Interviewees expressed concern about the impact of federal and state budget cuts on special education services including out-of-district placements and hiring of special education teachers. A couple of interviewees noted that some services—including transportation and before and after-school care—have already been cut back in some districts. Reductions in the special education aide workforce, interviewees explained, are especially concerning as these professionals provide critical hands-on support to special needs students during the school day. One interviewee who works with families stated that, *"Families are coming out of the woodwork concerned about where the money is going to come from for their child's*

*safety, because the parents of these kids, especially the medically complex kids, are really trusting the school district to keep their child safe.”*

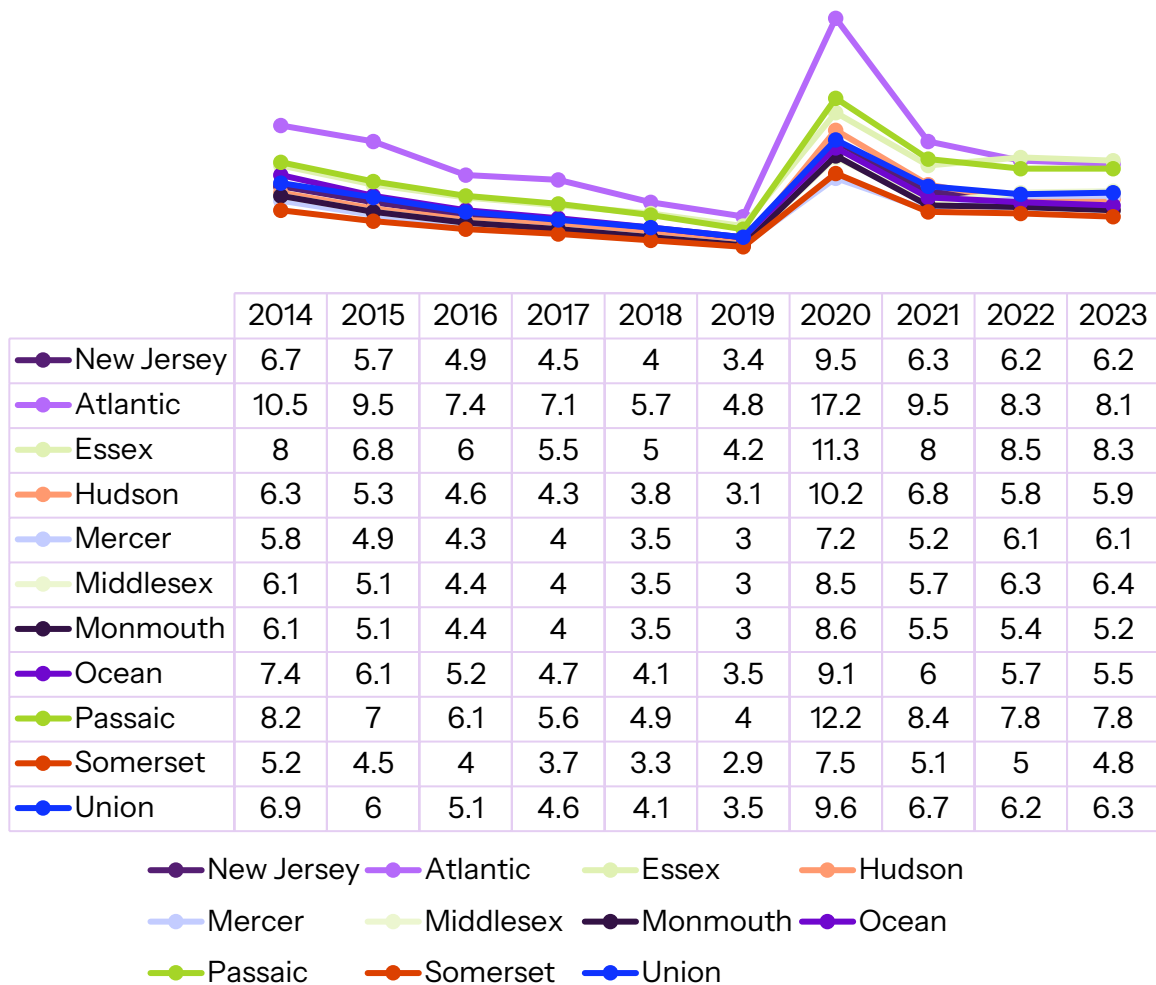
When describing their interactions with school systems, interviewees, parent/caregiver survey respondents, and focus group participants shared mixed experiences. While New Jersey is seen as having good services for students with special needs, this varies by school district and students’ needs. A couple of interviewees observed that many parents do not understand the special education system and the options that might be available to their children which limits their children’s access to these important services. Citing an example, one interviewee stated: *“Parents don’t know that they can ask for a behavioral assessment. They don’t know that they can ask for these different services specific to their situation. It’s very difficult because schools aren’t really giving the right information to help families move forward.”*

One challenge, participants noted, is that medical providers’ assessments and recommendations are often key to accessing the right services for students through IEPs or 504 plans. As one interviewee stated, *“A doctor writing a recommendation letter can make a significant difference in a child obtaining services in the school setting.”* However, participants shared that there is a lack of communication between education and healthcare systems, creating barriers to accessing the correct services and leaving parents and children caught in the middle. One survey respondent wrote, *“We’ve had medication side effects and with no communication [between provider and school]; it’s hard to get everyone on board.”* A parent focus group participant echoed this saying, *“Often parents are the go-between for doctors and the school. We have enough on our plate to then also have to facilitate this communication.”*

### **Employment and Workforce**

Employment can confer income, benefits, and economic stability – factors that promote health. Data from the Bureau of Labor Statistics show that unemployment rates in New Jersey declined from a high during the pandemic and have remained steady in recent years at slightly over 6%, as shown in the figure on the subsequent page. Of the ten counties in which CSH has locations, Atlantic, Essex, and Passaic have experienced the highest unemployment rates, 8.1%, 8.3% and 7.8% in 2023, respectively.

**Figure 14. Unemployment Rate, by State and County, 2014-2023**

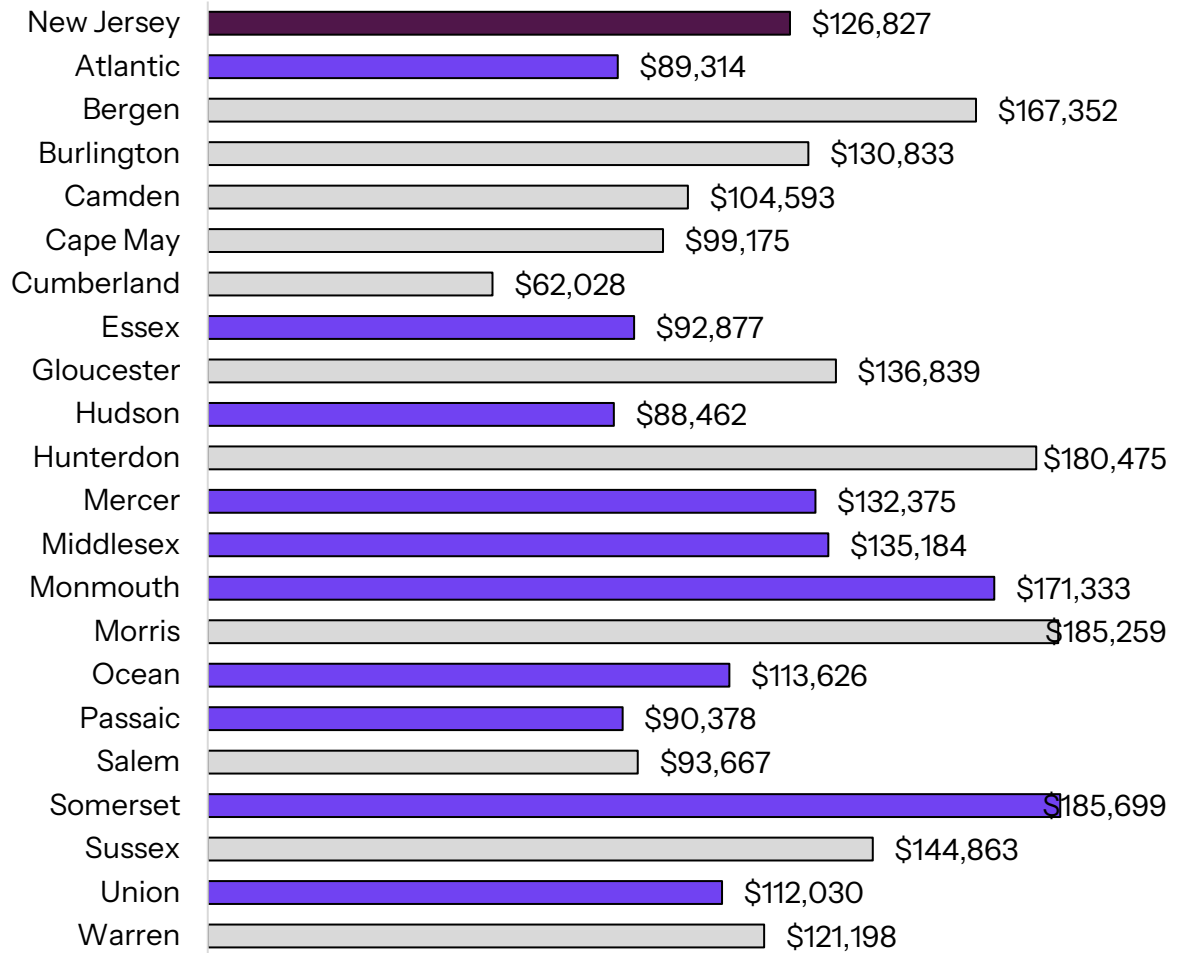


DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2014-2023

### Income and Financial Security

Income is a powerful social determinant of health that influences where people live and their ability to access resources that affect health and well-being. Community economic indicator data show that the median household income for New Jersey is \$126,827 (Figure 15). In six of the ten counties in which CSH facilities are located (Atlantic, Essex, Hudson, Ocean, Passaic, and Union), the median household income is lower than the state.

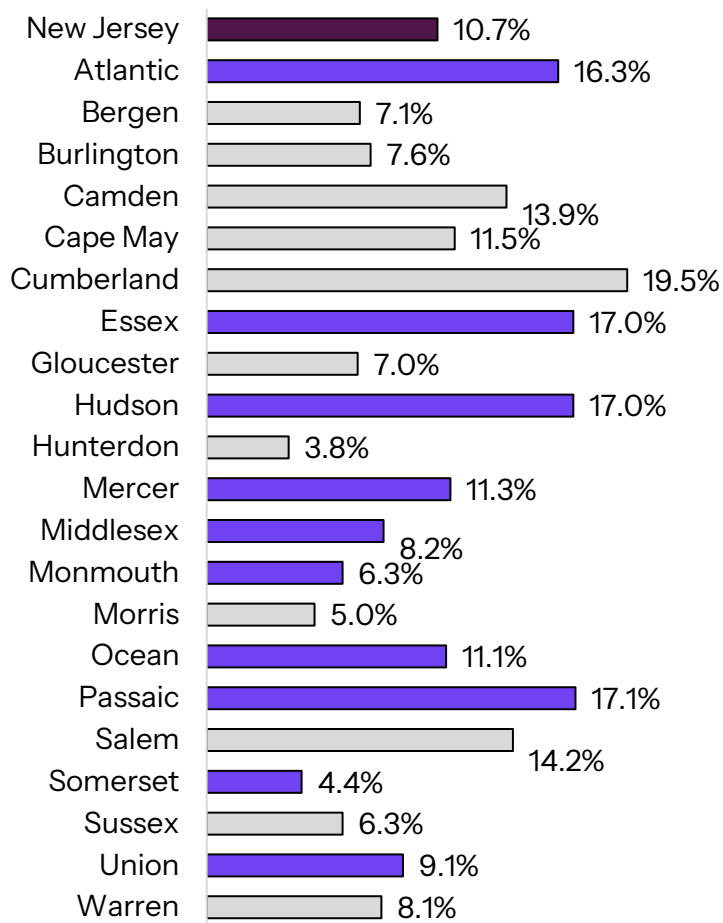
**Figure 15. Median Household Income for Households with Children Under 18, by State and County, 2019–2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019–2023

Slightly over 10% of families with children under age 18 in New Jersey live below the poverty line (Figure 16). In six (Atlantic, Essex, Hudson, Mercer, Ocean, and Passaic) of the ten counties in which CSH facilities are located, the percentage of families living below the poverty line is higher than the percentage in New Jersey. In Essex, Hudson, and Passaic counties, about 17% of children under age 18 live below the poverty line.

**Figure 16. Percent Families with Children Under Age 18 Below Poverty Level, by State and County, 2019–2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019–2023

A 2022 report about financial hardship uses the ALICE (Asset Limited, Income Constrained, Employed) metric to assess financial hardship among people with disabilities. The ALICE metric recognizes that many households may be above the federal poverty line (FPL) but do not have incomes sufficient to afford the basics in the communities where they live. These data, from 2019, show that 51% of people with disabilities nationally live below the ALICE threshold: this includes 18% living in poverty and another 34% living above the FPL but below the ALICE threshold. In New Jersey, 47% of people with disabilities live below the ALICE threshold: 14% below the FPL and another 33% above the FPL but below the ALICE threshold.<sup>15</sup>

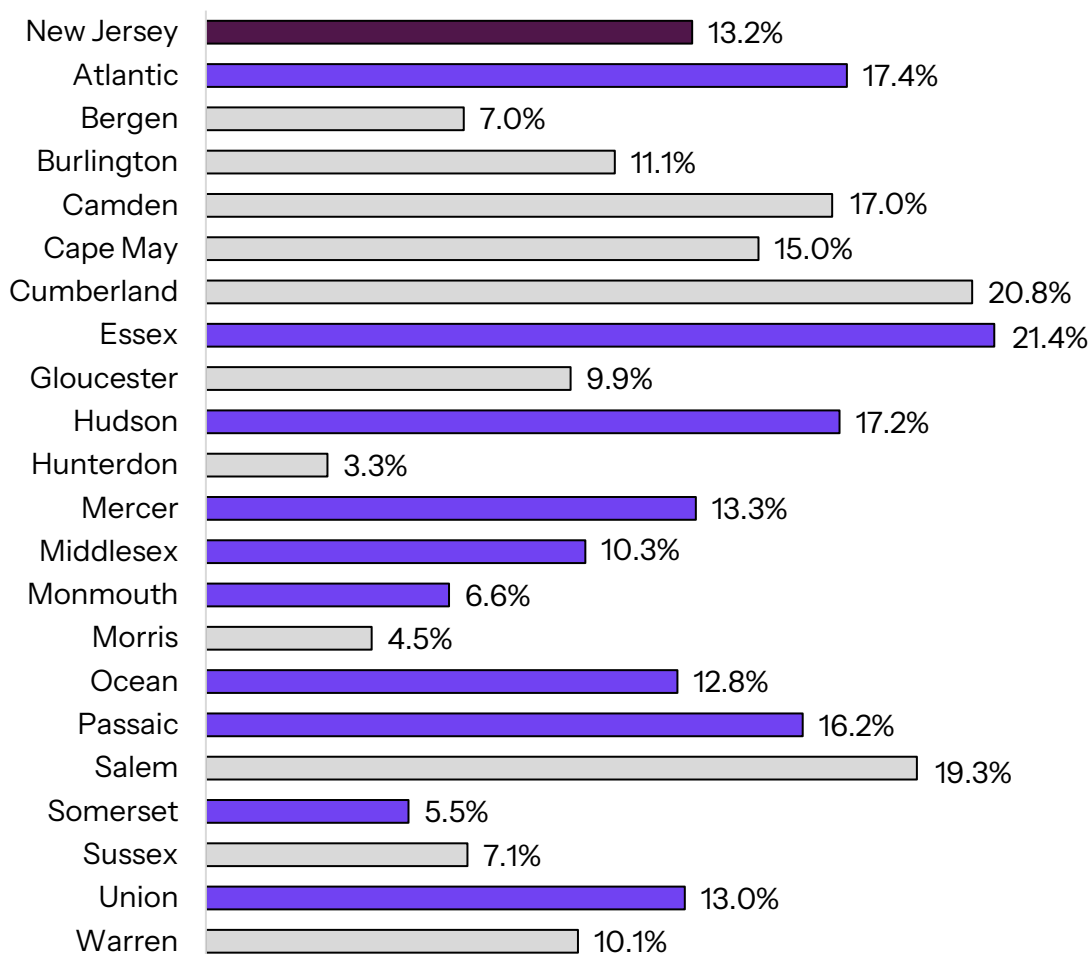
<sup>15</sup> *ALICE in Focus: Financial hardship among people with disabilities*. July 2022. United for ALICE. <https://www.unitedforalice.org/Attachments/ALICEInFocus/ALICE-in-Focus-Disabilities-National.pdf>

Several focus group and survey respondent parents/caregivers talked about the economic challenges associated with caring for children with special healthcare needs. They mentioned the cost of equipment, which is not always covered by insurance, as well as expenses associated with therapies, transportation, and housing. Focus group parents and survey respondents also stated that camps and sports and enrichment programs can be costly for families and eligibility for financial support is limited. Finally, for some families an additional cost is paying for legal assistance to obtain school-based services or out-of-school placements from their school districts.

### Food Insecurity and Healthy Eating

While many food access barriers are related to income constraints, access may also be more challenging for residents due to geography and transportation challenges. In 2022, about 13% of New Jersey residents under the age of 18 were food insecure (Figure 17). Four (Atlantic, Essex, Hudson, and Passaic) of the ten counties in which CSH has locations had higher rates of child food insecurity than the state overall. In Essex County, over 20% of children under the age of 18 are food insecure.

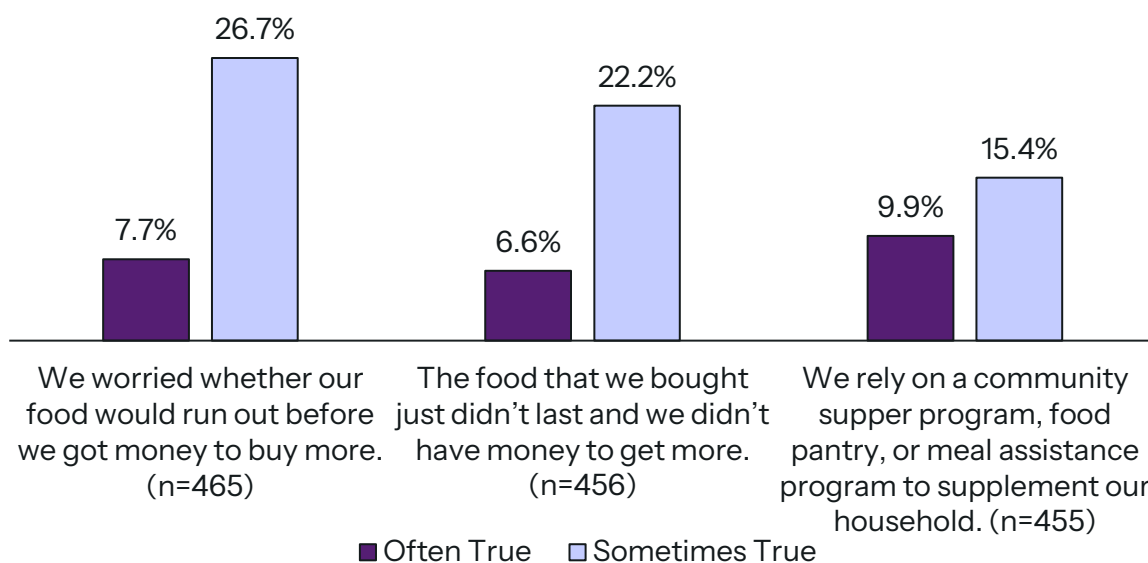
**Figure 17. Percent Under 18 Food Insecure, by State and County, 2022**



DATA SOURCE: Map the Meal Gap, Feeding America, 2022

As food prices have risen, food insecurity has become a concern for many families, including those with special needs children. Families with special needs children often have additional expenses to care for their children, which can create greater financial pressures, particularly on lower income families. CSH Community Survey data about food insecurity indicate that 7.7% of respondents who were parents/caregivers of special needs children often worried about whether their food would run out before they got money to buy more, while 26.7% of respondents indicated that they sometimes worried about this (Figure 18). A higher proportion of Black and Hispanic respondents and a higher proportion of respondents who have public health insurance reported food insecurity and use of food programs than other groups (data in Appendix E). Among survey respondents, 8.6% reported that they received food assistance from a hospital-based program over the past 12 months. Black, Asian and Hispanic survey respondents were more likely to report using hospital-based food programs than White respondents; respondents with public insurance were more likely to report this than those with private insurance (data in Appendix E). Data from the CSH SDOH screening survey indicate that 23.7% of CSH families surveyed between January and September 2024 were food insecure.<sup>16</sup>

**Figure 18. Percent of Community Survey Respondents Reporting Difficulty with Food Access, among Parents/Caregivers, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

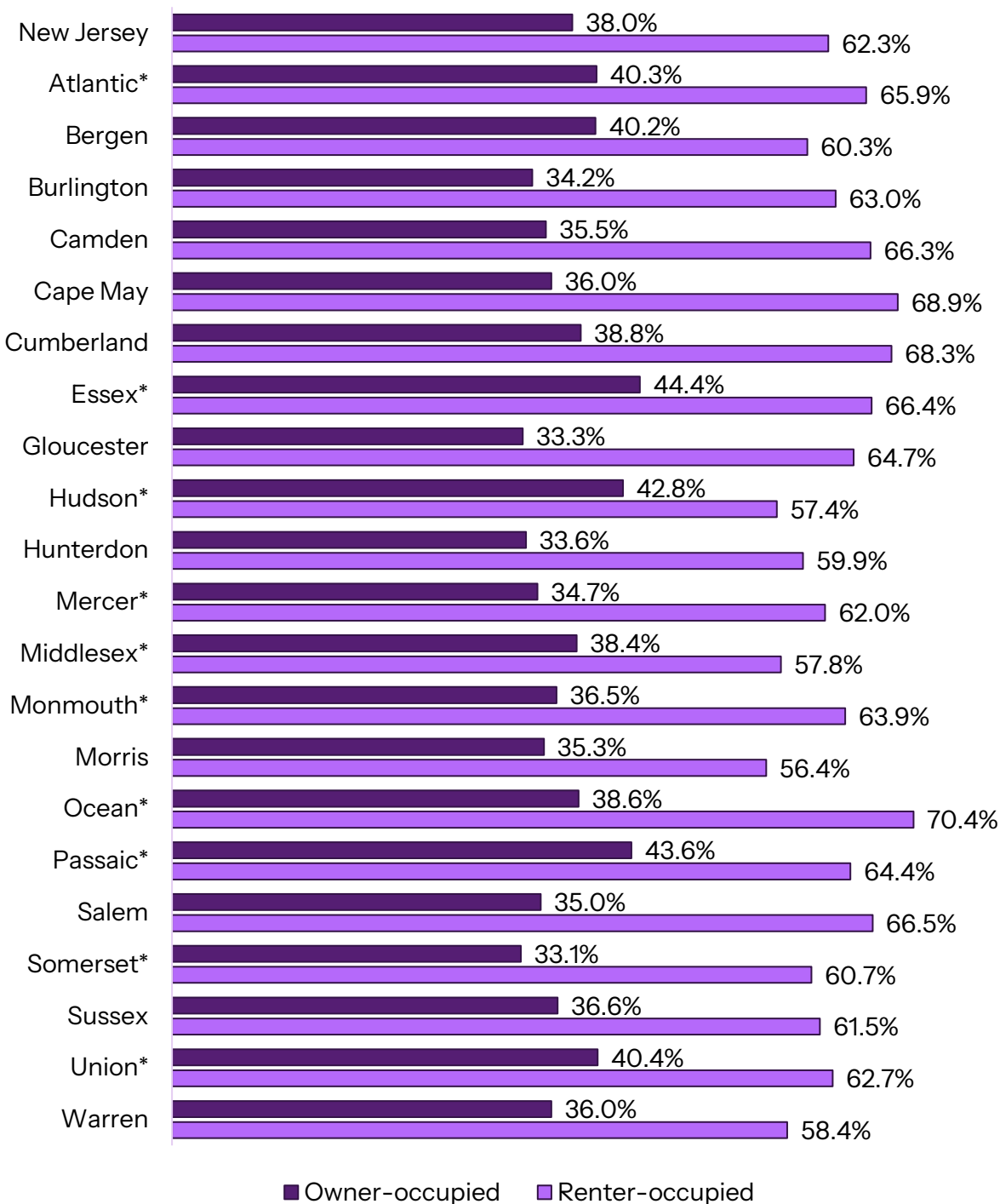
### Affordable Housing

Safe and affordable housing is integral to life, health, and well-being. American Community Survey data from 2019–2023 indicate that in New Jersey, 38.0% of homeowners and 62.3% of renters spend 30% or more of their household income on housing costs (Figure 19). In five (Atlantic, Essex, Hudson, Passaic, and Union) of the ten counties with CSH locations, a higher proportion of homeowners than the state spend 30% or more of their household income on housing costs. Similarly, in six (Atlantic, Essex, Monmouth, Ocean, and Passaic) of the ten

<sup>16</sup> Data collected from 17,048 screenings, conducted January – September 2024.

counties with CSH locations, a higher proportion of renters than the state spend 30% or more of their household income on housing costs.

**Figure 19. Percent Households Whose Housing Costs are 30% or More of Household Income, by State and County, 2019-2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

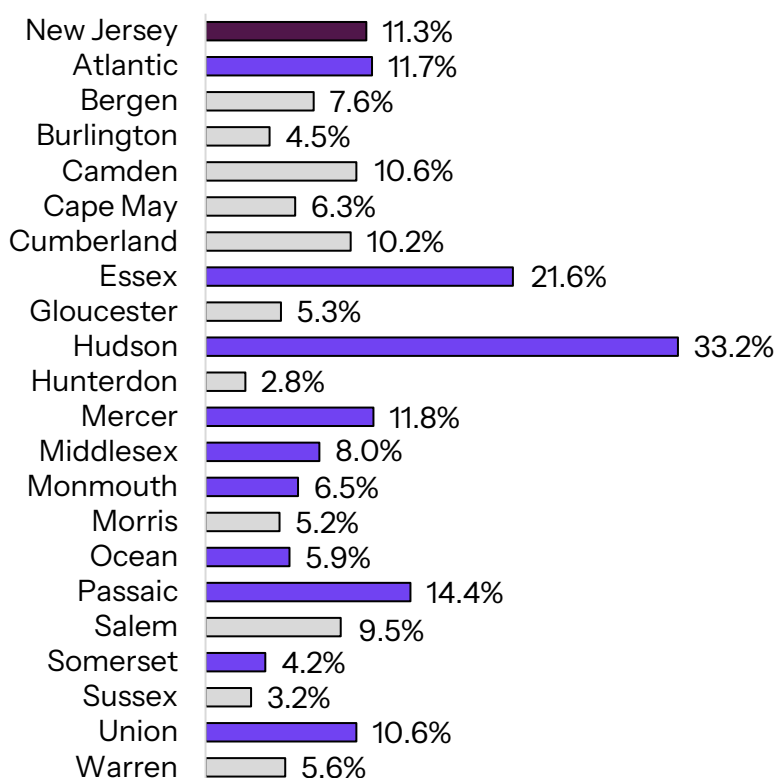
Data from the ALICE report indicate that in 2019, 61% of people with disabilities below the ALICE threshold were paying 35% or more on rent and 60% were paying 35% or more on mortgage costs; this compares to 57% and 38%, respectively, for people with disabilities living below the ALICE threshold nationally.<sup>17</sup>

Data from the CSH SDOH screening survey conducted in 2024 identified that 4.6% of CSH families were without steady housing and another 9.6% were concerned with losing their current housing. When asked about housing issues, utility shut off (9.4%), pests (7.1%), and mold (3.7%) were most frequently mentioned. While housing was not a prominent topic in the CSH focus group or the survey, a couple of parents mentioned challenges finding housing, especially housing that is wheelchair accessible.

### Transportation

According to the 2019–2023 American Community Survey 11.3% households in New Jersey did not have access to a vehicle (Figure 20). Among the ten counties with CSH locations, three (Essex, Hudson, and Passaic) have a higher proportion of households without access to a vehicle than the state. Notably, one third of Hudson County households and almost one quarter of Essex County households do not have access to a vehicle.

**Figure 20. Percent Households Without Access to a Vehicle, by State and County, 2019–2023**

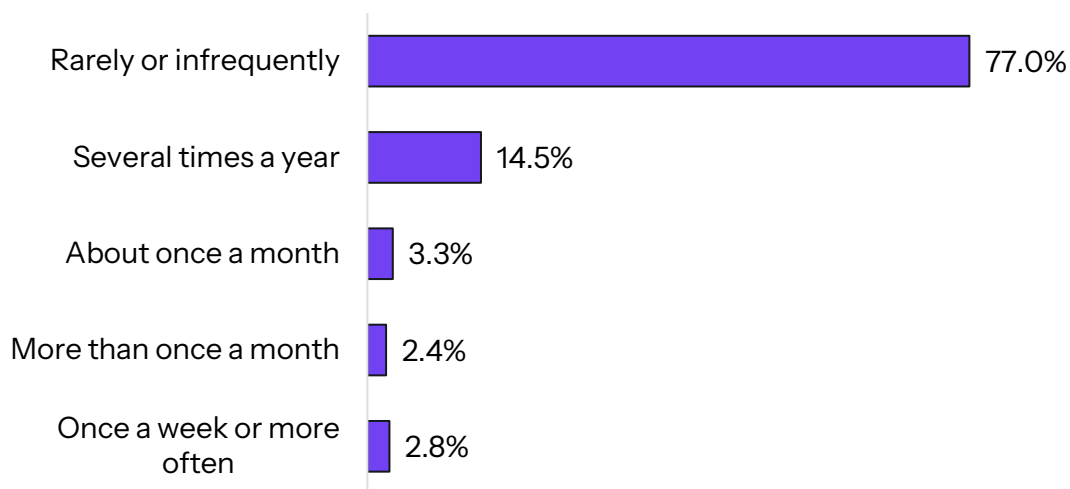


DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019–2023

<sup>17</sup> *ALICE in Focus: Financial hardship among people with disabilities*. July 2022. United for ALICE. <https://www.unitedforalice.org/Attachments/ALICEInFocus/ALICE-in-Focus-Disabilities-National.pdf>

Slightly less than 25% of parent/caregiver respondents to the community survey reported that they faced some transportation barriers, with the highest proportion (14.5%) reporting that they faced these challenges several times a year (Figure 21). Respondents with public insurance were more likely to report transportation barriers than those with private insurance (data in Appendix E). Data from the CSH SDOH screening survey show that 7.9% of CSH families screened reported general transportation issues and 2.8% reported school transportation issues.

**Figure 21. Percent of Community Survey Respondents Reporting Frequency of Transportation Barriers, among Parents/Caregivers, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

CSH community survey respondents identified transportation barriers as a challenge for some families with special needs children. While some healthcare providers offer transportation to appointments, respondents reported that not all do and many therapy services do not, so families must rely on other sources. An interviewee stated that Perform Care, the state’s System of Care provider, provides transportation cards for reduced bus fare, and some parents/caregivers reported that they use Uber or Lyft to get to appointments. Families also use Access Link and Modivcare, although some parents/caregivers reported challenges with these services including difficulty scheduling rides and long wait times to be picked up.

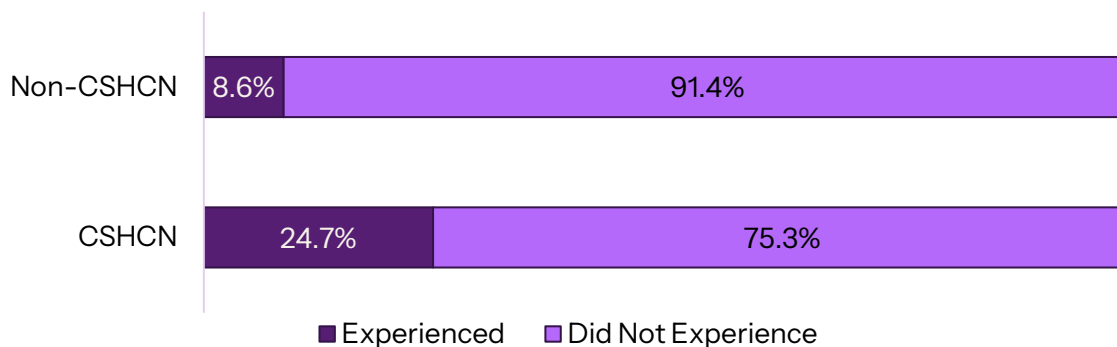
*“My 18 year-old wants to be more independent, and transportation is a key barrier. She could attend OT or a support group on her own if she had transportation.”*  
– Community survey respondent

Lack of transportation is a substantial challenge for transition-age youth and young adults who would like to be more independent. Parent and young adult focus group participants frequently mentioned that lack of transportation hindered their young adult children’s ability to access employment as well as social and recreational opportunities.

## Safety

Data from the 2022–2023 National Survey of Children’s Health indicate that a higher proportion of children with special healthcare needs (24.7%) experienced two or more adverse childhood experiences<sup>18</sup> than those without special needs (8.6%) (Figure 22).

**Figure 22. Percent Children Who Experienced Two or More Adverse Childhood Experiences, by CSHCN Status, New Jersey, 2022–2023**



DATA SOURCE: National Survey of Children’s Health, 2022–2023

NOTE: CSHCN stands for Children with Special Healthcare Needs.

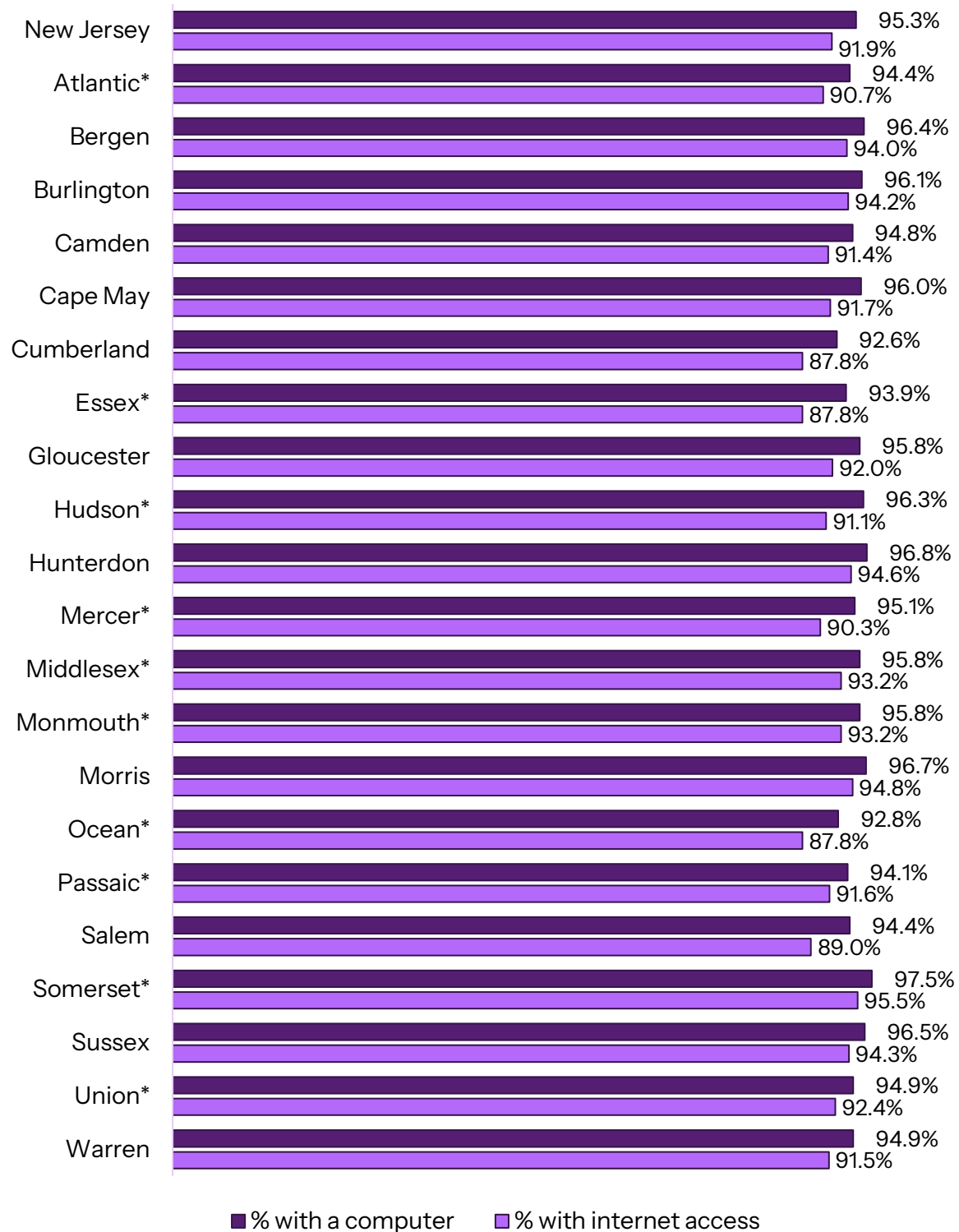
## Technology

Data from the 2019–2023 American Community Survey indicate that in New Jersey, approximately 95% of households had a computer and 92% had internet access (Figure 23). Of the ten counties served by CSH, Essex and Ocean counties had the lowest rates of access to a computer and the internet. In Essex County, 93.9% of households have access to a computer and 87.8% have access to the internet. In Ocean County, 92.8% of householders have access to a computer and 87.8% have access to the internet. Data from the ALICE report indicate that in New Jersey, 56% of people with disabilities living below the ALICE threshold had high-speed internet access, compared to 53% nationally.<sup>19</sup>

<sup>18</sup> Adverse childhood experiences (ACEs) in the NSCH are defined as one or more of the following: Parent/guardian divorced or separated; Parent/guardian died; Parent/guardian served time in jail; Saw or heard parents or adults slap, hit, kick, punch one another in the home; Was a victim of violence or witnessed violence in his or her neighborhood; Lived with anyone who was mentally ill, suicidal, or severely depressed; Lived with anyone who had a problem with alcohol or drugs; Was treated or judged unfairly because of his or her race or ethnic group.

<sup>19</sup> *ALICE in Focus: Financial hardship among people with disabilities*. July 2022. United for ALICE. <https://www.unitedforalice.org/Attachments/ALICEInFocus/ALICE-in-Focus-Disabilities-National.pdf>

**Figure 23. Percent Households with a Computer and Internet Access, by State and County, 2019-2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

# Community Health Issues

Understanding community health issues is a critical step of the assessment process. The disparities underscored by these issues mirror the historical patterns of systemic, economic, and racial inequities experienced for generations across the United States.

## Overall Child Health

The National Survey of Children’s Health (NSCH) from 2022-2023 provides a picture of overall health among children and youth, including those with special healthcare needs. Data are presented for New Jersey and compared to the nation; data are not available at the county level. In 2022-2023, 91.3% of children in New Jersey were described as being in “excellent” or “very good” health, a proportion similar to the nation (Table 3).

**Table 3. Overall Child Health, by U.S. and State, 2022-2023**

Health Status	United States	New Jersey
Excellent or Very Good	90.0%	91.3%
Good	8.6%	6.9%
Fair or Poor	1.4%	1.8%

DATA SOURCE: National Survey of Children’s Health, 2022-2023

## Overweight, Obesity, and Physical Activity

Data about risk behaviors among high school youth in New Jersey come from the 2023 Youth Risk Behavior Survey (YRBS) and are presented in Table 4. Data are not available at the county level. In 2023, 12.3% of New Jersey high school students were obese while 16.7% were overweight. About 6% of students reported that year that they had not consumed fruit in the week prior to the survey.

**Table 4. Percent High School Students Reporting Obesity, Overweight, or Fruit Consumption, by State, 2023**

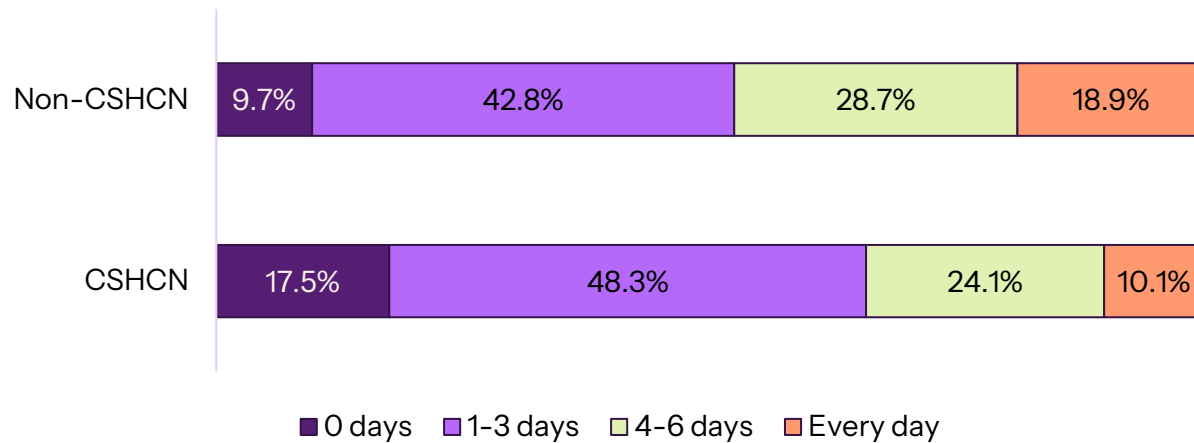
New Jersey	%
Obesity	12.3%
Overweight	16.7%
No Fruit Consumption in Past Week	6.2%

DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2023

NOTE: No Fruit Consumption: Did not eat fruit or drink 100% fruit juices. Includes orange juice, apple juice, or grape juice, not counting punch, Kool-Aid, sports drinks, or other fruit-flavored drinks, during the 7 days before the survey.

Data from the 2022-2023 NSCH indicate that a smaller proportion of children with special healthcare needs than other children engage in regular physical activity. About 18% of special needs children did not engage in any physical activity in the week prior to the survey, compared to 10% of other children (Figure 24).

**Figure 24. Percent Children Ages 6-17 Participating in Physical Activity During the Past Week, by Frequency and CSHCN Status, by State, 2022-2023**

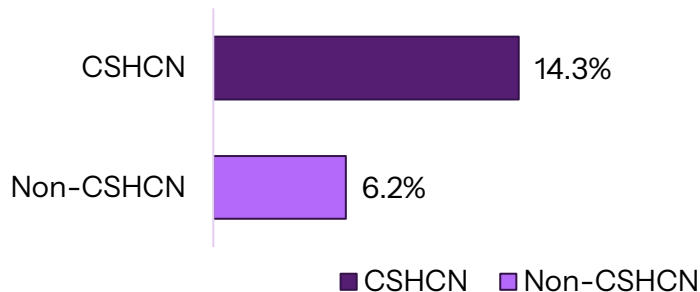


DATA SOURCE: National Survey of Children's Health, 2022-2023

NOTE: CSHCN stands for Children with Special Healthcare Needs.

According to NCSH results, 14.3% of parents of children with special healthcare needs in New Jersey have been told by a doctor or other health provider that their children are overweight, compared to 6.2% of other children (Figure 25).

**Figure 25. Percent Children Ages 6-17 Who Identified as Overweight by a Doctor or Other Health Provider, by CSHCN Status, by State, 2022-2023.**



DATA SOURCE: National Survey of Children's Health, 2022-2023

NOTE: CSHCN stands for Children with Special Healthcare Needs.

## Mental Health and Behavioral Health

Table 5 presents data about mental health and substance use for New Jersey high school youth; data are not available at the county level. In 2023, 36.3% of New Jersey high school students reported feeling persistently sad or hopeless in the prior year and 14% reported that they had seriously considered suicide. Additionally, about 27% reported that they consume alcohol and 18% reported that they vaped.

**Table 5. Percentage of High School Youth Reporting Mental Health Issues and Substance Use During Past Year, by State, 2023**

Mental Health	%
Feeling Persistently Sad or Hopeless	36.3%
Seriously Considered Suicide	14.0%
Attempted Suicide	5.2%
Substance Use	%
Current Cigarette Use	2.8%
Current Electronic Vapor Product Use	18.2%
First Drank Alcohol Before Age 13	12.9%
Current Alcohol Use	27.2%
Current Binge Drinking	12.5%
Current Marijuana Use	13.6%

DATA SOURCE: Youth Risk Behavior Survey (YRBS), Centers for Disease Control and Prevention, 2023

Mental health was identified as a challenge for families with special needs children across interviews, in the parent focus group, and among community survey respondents. Participants noted increased anxiety and depression among students with special needs, which they attributed to multiple factors, including the lingering effects of the COVID-19 pandemic. As one interviewee shared *“Some of some of my [special needs] kids have incredibly high IQ scores, but cannot, for the life of them get to school, so they’ll miss two and three and four months of school, because their anxiety or their depression is so severe and they can’t function in reality.”*

Participants explained that accessing mental health services for special needs children and youth is difficult. As described in the Access to Services section below over half of parent/caregiver survey respondents identified behavioral/mental healthcare as very hard or hard to access in their communities.

While Perform Care, the State’s System of Care provider, helps parents/caregivers to find mental health services for their children, lack of providers makes it difficult for families to actually obtain these services. One interviewee explained, *“There’s just not enough [providers] to meet the need. And that’s particularly true for the children’s*

*“Mental health, such as psychology and psychiatry, to the extent which the patient needs, is extremely hard to find after a diagnosis or referral.”*

– Young adult community survey respondent

*system of care, where you often see kids with the most intensive needs trying to access services and we just don't have them."*

Parents/caregivers reported long waitlists for appointments with mental health professionals and also noted that many providers are not taking new patients. They shared experiences of having to call many different providers to find an opening or get on a waitlist. One caregiver shared their experience saying, *"It is hard to get an appointment. I have to call daily to see if anyone cancelled and there is not a wait list."*

Another factor constraining availability of mental health services, participants explained, is that a growing number of mental health providers are not accepting Medicaid, and in some cases, are also not accepting private insurance. This means that families must pay out-of-pocket for services which creates additional difficulties for lower income families. As one parent summarized: *"In most cases mental health providers are not available. And then, even if the supply is there, accessing it is a challenge because a lot of these people have written off insurance entirely. So now you're paying for it."* Participants also explained that families who are able to access mental health services through insurance often find limitations on the number of sessions or scope of services covered.

Parents/caregivers also shared challenges finding mental health providers who have expertise working with children and youth who have intellectual or developmental disabilities. Many mental health providers are "generalists," parents/caregivers

*"We need providers who can work within individuals with autism but use a variety of methods and providers who know how to work with people with developmental delays."*  
- Community survey respondent

and interviewees observed, and may not be able to distinguish between behavioral issues that are associated with a neural development diagnosis and those deriving from a mental health condition. Further, a couple of people explained that this lack of understanding can hinder identification of appropriate interventions. One example cited by an interviewee is the use of applied behavior analysis (ABA) as the go-to intervention for those with autism when other approaches may be more effective.

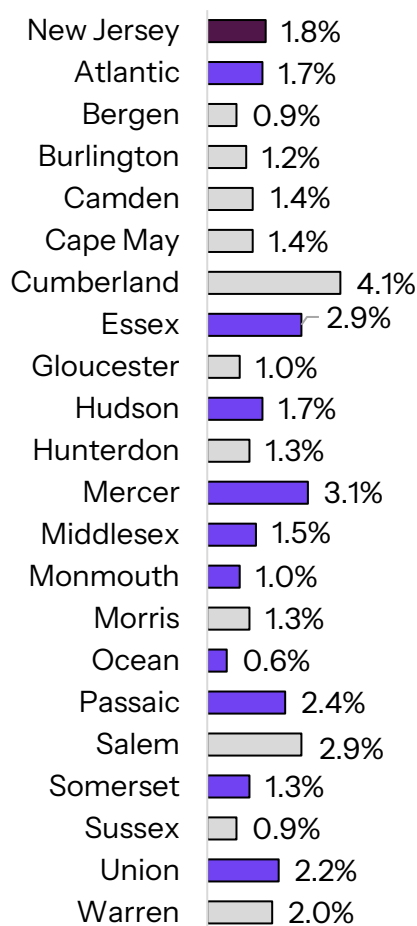
Schools also play a role in supporting student mental and behavioral health; however, participants explained, these services have been cut back as school budgets have tightened. As a consequence, some parents and interviewees shared, special needs students are increasingly suspended because schools are unable to manage behavior issues. One interviewee stated, *"These schools don't have the funds even to put in these general programs that are recommended by the state. And instead, they're just saying, 'well, this one gets suspended.'"*

## **Environmental Health**

A healthy environment is associated with a high quality of life and good health. Environmental factors are various and far-reaching and include exposure to hazardous substances in the air, water, soil, or food; natural disasters and climate change; and the built environment. Figure 26 shows that 1.8% of children in the state of New Jersey had elevated blood lead levels in 2022. This proportion is higher than the 0.6% of New Jersey children with

elevated blood lead levels reported in the 2022 CHNA. A higher proportion of children in four (Essex, Mercer, Passaic, and Union) of the ten counties with CSH locations had higher blood lead levels than the state.

**Figure 26. Percent Children with Elevated Blood Levels, by State and County, 2022**

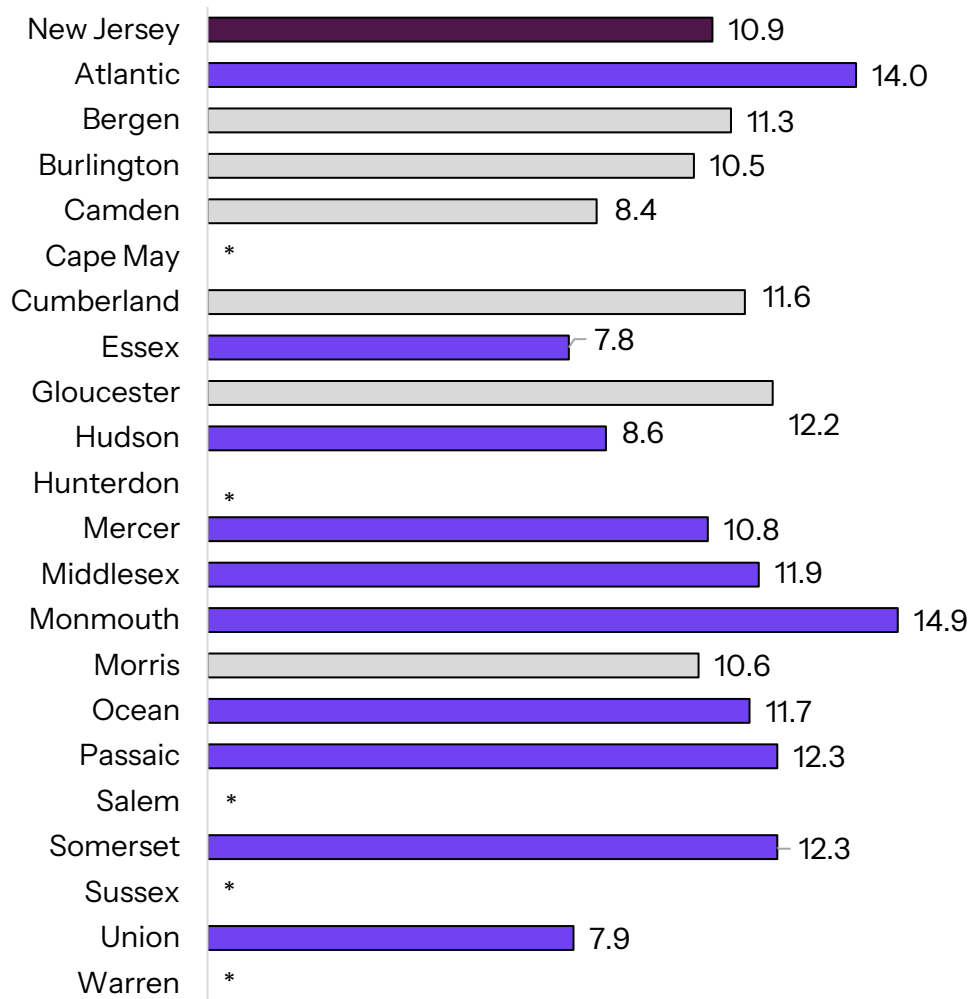


DATA SOURCE: New Jersey Department of Health, 2024

### Infectious and Communicable Diseases

COVID-19 data are available from the New Jersey Department of Health. Scientific breakthroughs which enabled the rapid development of COVID-19 vaccines coupled with a successful public health campaign, led to a sharp decline in COVID-19 deaths. By May 2023, New Jersey had administered nearly 20 million COVID-19 vaccine doses. Approximately 8.5 million residents—95% of the state’s population—had received at least one dose, and over 7 million (79% of residents) were fully vaccinated with two doses. Launched in late 2020, this highly effective vaccination effort significantly reduced COVID-19 mortality across the state. In 2023, the COVID-19 death rate in New Jersey was 10.9 per 100,000 population (Figure 27). Rates in six (Atlantic, Middlesex, Monmouth, Ocean, Passaic, and Somerset) of the ten counties with CSH locations were higher than the state.

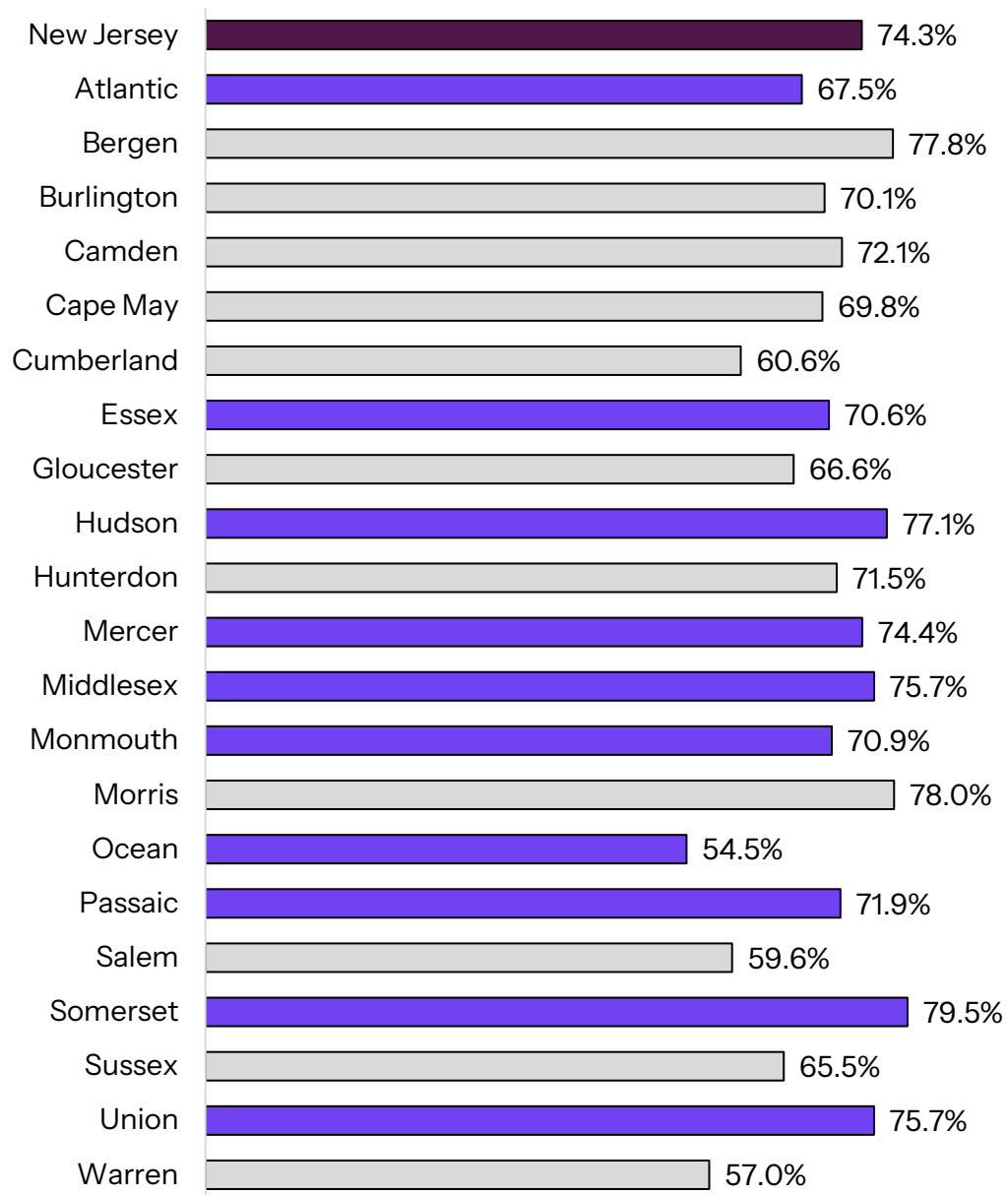
**Figure 27. COVID-19 Death Rate, Age-Adjusted, per 100,000 Population, by State and County, 2023**



DATA SOURCE: Death Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health via New Jersey State Health Assessment Data (NJSHAD), 2025  
 NOTE: Asterisk means that rate does not meet National Center for Health Statistics standards of statistical reliability for presentation.

Data about COVID-19 vaccination show that 74.3% of New Jersey residents over the age of 5 were fully vaccinated in 2023 (Figure 28). Four of the ten CSH counties, Hudson, Middlesex, Somerset, and Union, have vaccination rates higher than the state.

**Figure 28. Percent Population with Completed Primary Series COVID-19 Vaccinations, by State and County, 2023**

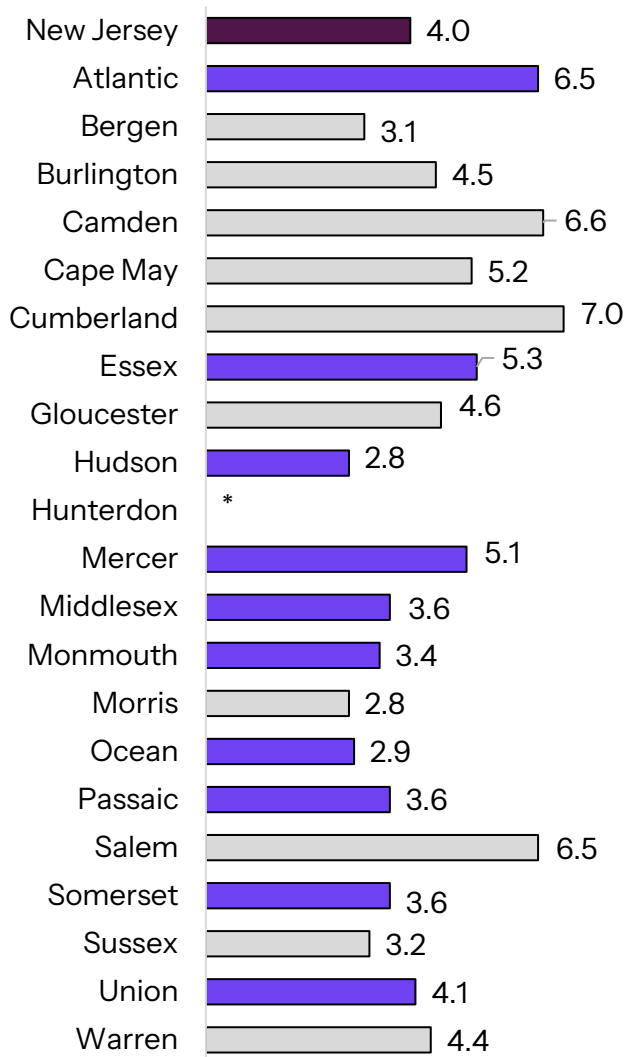


DATA SOURCE: New Jersey Department of Public Health, COVID-19 Dashboard, 2024

## Maternal and Infant Health

As shown in Figure 29, the infant mortality rate for New Jersey overall was 4.0 per 100,000 births in 2017–2021. Three (Atlantic, Essex, and Mercer) of the ten counties with CSH locations had infant mortality rates higher than the state.

**Figure 29. Infant Mortality Rate, per 100,000 Population, by State and County, 2017–2021**



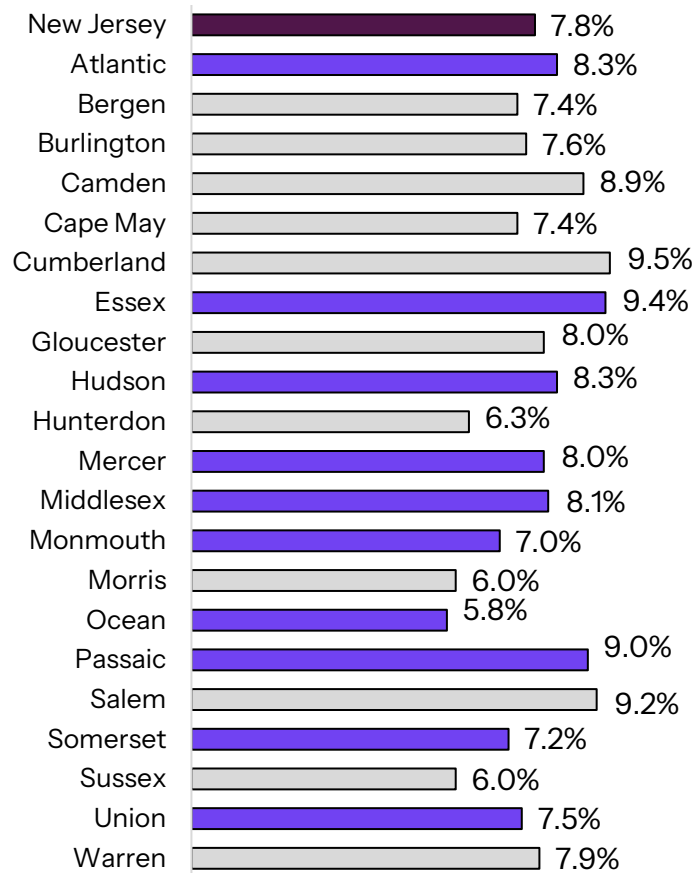
DATA SOURCE: Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health via New Jersey State Health Assessment Data (NJSHAD), 2023

Low Birth Weight (LBW) infants, defined as those weighing under 2500 grams at birth, may require intensive care at birth and are at higher risk of developmental disabilities and chronic illnesses throughout life. LBW infants have higher healthcare costs and lengths of stay.

As shown in Figure 30, New Jersey State Health Assessment Data (NJSHAD) from 2018–2022 indicate that 7.8% of births in the state were LBW. Over this same time period, 1.3% of

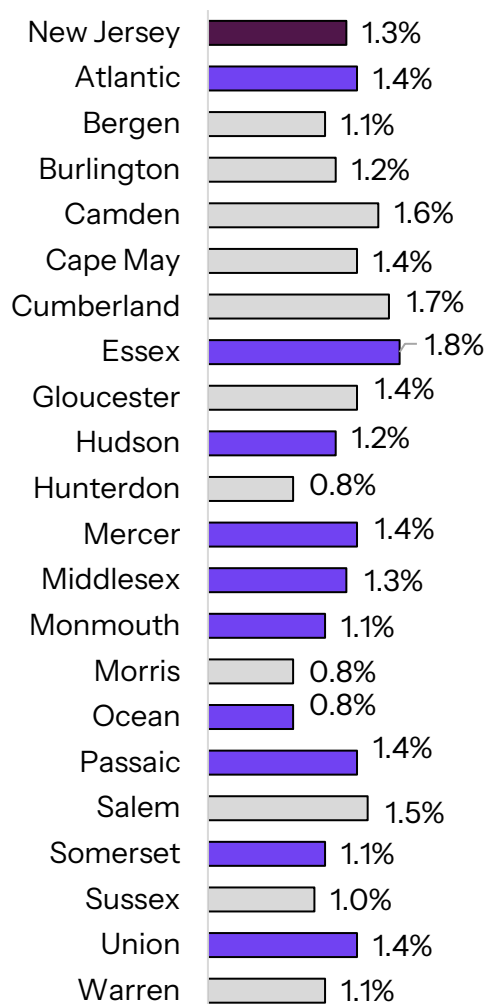
births were classified as very low birthweight (under 1500 grams) (Figure 31). The CSH counties of Atlantic, Essex, Hudson, Mercer, Middlesex, and Passaic had higher rates of LBW than the state.

**Figure 30. Percent Low Birthweight Births, by State and County, 2018-2022**



DATA SOURCE: Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health via New Jersey State Health Assessment Data (NJSHAD), 2024  
 NOTE: Infants born weighing under 2500 grams are classified as low birth weight.

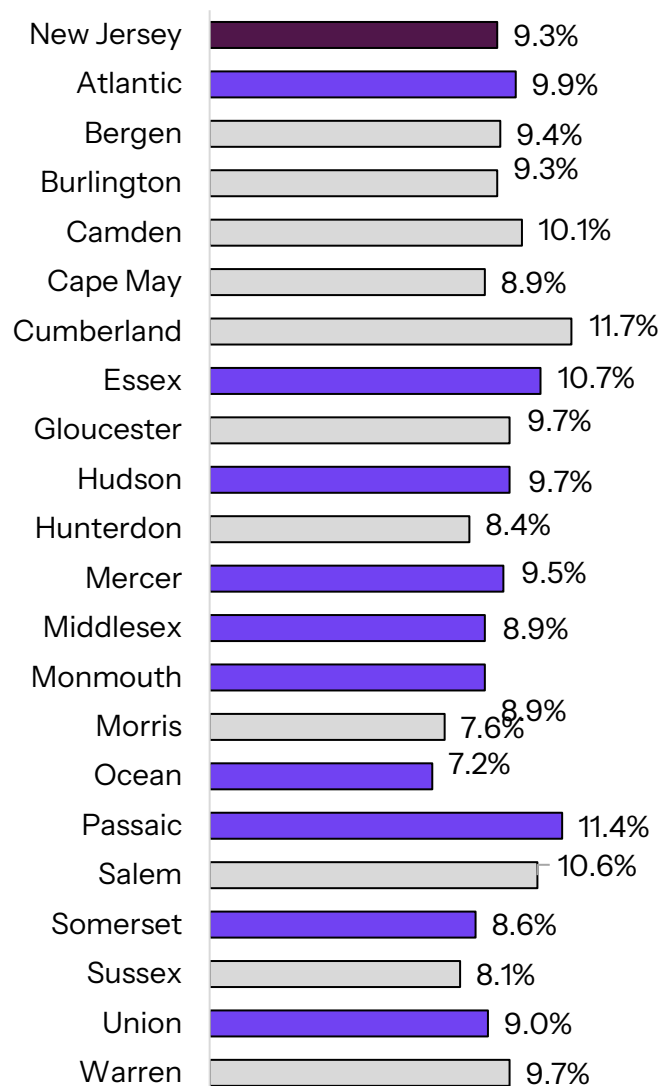
**Figure 31. Percent of Very Low Birthweight Births, by State and County, 2018-2022**



DATA SOURCE: Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health via New Jersey State Health Assessment Data (NJSHAD), 2024  
 NOTE: Infants born weighing under 1500 grams are classified as very low birth weight.

Data about preterm births, those before 37 weeks, indicate that 9.3% of births in New Jersey from 2018-2022 were preterm (Figure 32). Five (Atlantic, Essex, Hudson, Mercer, and Passaic) of the ten counties with CSH locations had higher rates of preterm births than the state.

**Figure 32. Percent Preterm Births, by State and County, 2018-2022**

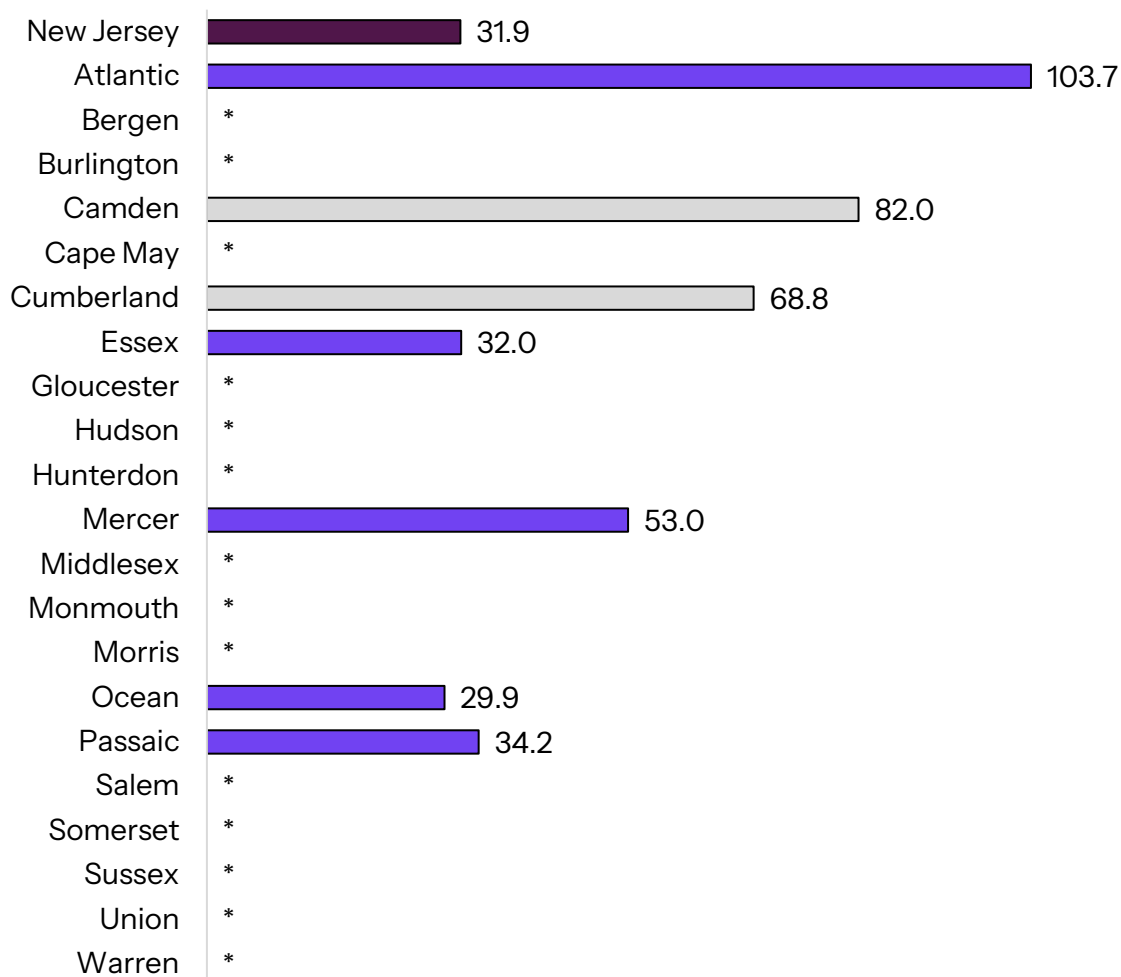


DATA SOURCE: Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health via New Jersey State Health Assessment Data (NJSHAD), 2024

NOTE: Infants in gestation for less than 37 weeks.

Data about neonatal abstinence syndrome (NAS) from the New Jersey Department of Health indicate that 31.9 births per 10,000 had NAS in 2023 (Figure 33). Data are not available for all counties; however, among the CSH counties for which data are available, three (Atlantic, Mercer, and Passaic) had NAS rates higher than the state. Of all New Jersey counties, Atlantic had the highest rates, at 103.7 births per 10,000.

**Figure 33. Neonatal Abstinence Syndrome (NAS) Rate per 10,000 Births, by State and County, 2023**



DATA SOURCE: New Jersey Department of Health, New Jersey Hospital Discharge Data Collection System, 2025

NOTE: The asterisk (\*) means that rates are not shown due to counts less than or equal to 20.

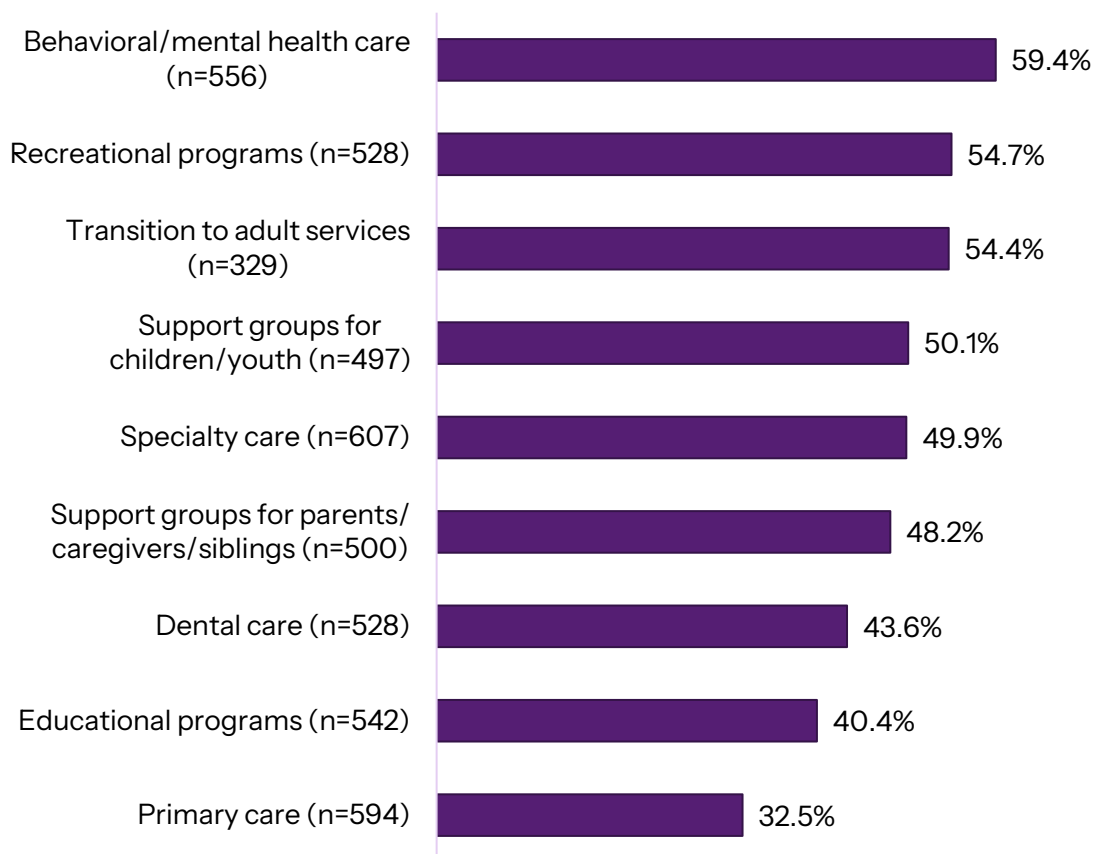
# Access to Services

As described earlier, parents and interviewees reported that, compared to other states, New Jersey has many resources to support children with special healthcare needs and their families. These include healthcare services as well as school- and community-based programs that support education and social development. Advocacy and service organizations support parents and families by providing resources and training and through family advocacy and support for systems and policy change. However, some programs and services are difficult to access for a variety of reasons.

## Services that are Difficult to Access

Those responding to the community survey were asked how easy or difficult it was to access various health and other programs and services for their children with special healthcare needs. As shown in Figure 34, about half of survey respondents identified numerous services as hard or very hard to access including behavioral/mental healthcare, recreational programs, and services that support preparing for adulthood. These three services were identified as the most difficult to access in the 2022 CSH community survey.

**Figure 34. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Healthcare Needs, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

Appendix E provides detailed charts of survey responses among parents/caregivers and other respondents, and by characteristics such as race/ethnicity, insurance status, and age of child among parent/caregiver respondents. Key findings from these analyses are presented in this section.

As shown in Table 6 about half of parent/caregiver survey respondents identified recreational programs, behavioral/mental healthcare, and services that support transition to adulthood as very hard or hard to access. In 2022, among parent/caregiver respondents, recreational programs were rated the most difficult to access, followed by behavioral/mental healthcare and transition to adult services. In 2019, recreational programs were the fourth most difficult. Support groups for both children/youth and parents and families were identified as among the top five services most difficult to access in the 2022 survey.

Among survey respondents who are involved in the lives of children with special healthcare needs in other ways (as other family member, friend, or someone who works with children), transition to adult services was identified as most difficult to access, followed by dental care and specialty care. In 2022, community survey respondents who were not parents/caregivers rated dental care as the most difficult service to access and transition to adult services as the second most difficult.

**Table 6. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Healthcare Needs, among Parents/Caregivers and Other Respondents, 2025**

	Parents/Caregivers	Other Respondents
1	Behavioral/mental healthcare (n=505) (58.4%)	Transition to adult services (n=39) (79.5%)
2	Recreational programs (n=480) (54.0%)	Dental care (n=37) (78.4%)
3	Transition to adult services (n=284) (50.7%)	Specialty care (n=44) (70.5%)
4	Support groups for children/ youth (n=453) (48.3%)	Support groups for children/ youth (n=39) (69.2%)
5	Specialty care (n=555) (48.1%)	Behavioral/mental healthcare (n=44) (68.2%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

Responses varied across survey respondents of different races/ethnicities. Recreational programs were identified as among the top two services most difficult to access for all racial/ethnic groups except White, non-Hispanic respondents (Table 7). Behavioral/mental health services were identified among the top three most difficult services to access for all groups except Asian, non-Hispanic respondents. Black and Asian non-Hispanic respondents reported that dental care is very difficult to access, while Hispanic and White and Asian non-Hispanic respondents reported that transition to adult services is hard or very hard to access.

**Table 7. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Healthcare Needs, among Parents/Caregivers, by Race/Ethnicity, 2025**

	<b>Black, non-Hispanic</b>	<b>Asian, non-Hispanic</b>	<b>White, non-Hispanic</b>	<b>Hispanic/Latino</b>	<b>Other/2+ Races, non-Hispanic</b>
<b>1</b>	Dental care (52.1%)	Transition to adult services (63.6%)	Behavioral/mental healthcare (67.2%)	Recreational programs (60.9%)	Recreational programs (60.0%)
<b>2</b>	Recreational programs (49.0%)	Recreational programs (55.0%)	Transition to adult services (62.0%)	Behavioral/mental healthcare (58.9%)	Behavioral/mental healthcare (53.3%)
<b>3</b>	Behavioral/mental healthcare (46.0%)	Dental care (47.4%)	Support groups for children/youth (57.5%)	Support groups for children/youth (57.1%)	Specialty care (50.0%)
<b>4</b>	Specialty care (42.1%)	Support groups for children/youth (47.1%)	Specialty care (55.8%)	Support groups for parents/caregivers/siblings (51.2%)	Primary care (46.7%)
<b>5</b>	Support groups for parents/caregivers/siblings (39.6%)	Support groups for parents/caregivers/siblings (42.1%)	Support groups for parents/caregivers/siblings (53.3%)	Transition to adult services (48.0%)	Support groups for children/youth (38.5%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the Black, non-Hispanic category ranged from n=47 to n=57. The number of respondents in the Asian, non-Hispanic category ranged from n=17 to n=23. The number of respondents in the White, non-Hispanic category ranged from n=120 to n=147. The number of respondents in the Hispanic/Latino category ranged from n=84 to n=98. The number of respondents in the Other/2+ Races, non-Hispanic category ranged from n=12 to n=16.

Challenges accessing behavioral/mental was the top challenge for parent/caregiver survey respondents regardless of insurance (Table 8). Both groups also identified specialty care as hard or very hard to access.

**Table 8. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Healthcare Needs, among Parents/Caregivers, by Insurance Status, 2025**

	Private	Government plan
1	Behavioral/mental healthcare (59.2%)	Behavioral/mental healthcare (54.4%)
2	Transition to adult services (58.0%)	Recreational programs (52.5%)
3	Support groups for children/youth (56.2%)	Specialty care (44.7%)
4	Recreational programs (54.3%)	Transition to adult services (58.0%)
5	Specialty care (53.5%)	Support groups for parents/caregivers/siblings of children/youth (42.5%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the Private category ranged from n=81 to n=170. The number of respondents in the Government plan category ranged from n=81 to n=159.

Table 9 shows parent/caregiver responses by age of children with special healthcare needs. Accessing behavioral/mental health services for their children was a challenge for parents/caregivers with children across the age spectrum, with over half of respondents in each group identifying these services as hard or very hard to access. Parents/caregivers of younger children and adolescents rated these services as most difficult to access. Among parents/caregivers of older youth and young adults accessing services related to transition to adulthood were most difficult. Notably, two-thirds or more of survey respondents with older children rated services that support transition to adulthood as hard or very hard to access. Among parents/caregivers of younger children and those 15-18 years old specialty care was among the top five services most difficult to access. Dental care was among the top five services most difficult to access for parents/caregivers of the youngest and the oldest children.

**Table 9. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Healthcare Needs, among Parents/Caregivers, by Age of Child, 2025**

	Under 5	5-9 years	10-14 years	15-18 years	19+ years
<b>1</b>	Behavioral/ mental healthcare (53.1%)	Behavioral/ mental healthcare (59.0%)	Behavioral/ mental healthcare (52.9%)	Transition to adult services (70.8%)	Transition to adult services (65.7%)
<b>2</b>	Recreational programs (45.7%)	Recreational programs (56.1%)	Support groups for children/ youth (50.9%)	Specialty care (63.2%)	Behavioral/ mental healthcare (63.9%)
<b>3</b>	Specialty care (38.6%)	Specialty care (48.7%)	Recreational programs (50.8%)	Recreational programs (62.9%)	Dental care (58.8%)
<b>4</b>	Dental care (33.3%)	Support groups for parents/ caregivers/ siblings (46.0%)	Support groups for parents/ caregivers/ siblings (49.2%)	Behavioral/ mental healthcare (61.1%)	Support groups for parents/ caregivers/ siblings (58.6%)
<b>5</b>	Support groups for children/ youth (32.4%)	Educational programs (45.2%)	Transition to adult services (46.0%)	Support groups for children/ youth (60.0%)	Support groups for children/ youth (58.1%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the Under 5 category ranged from n=17 to n=44. The number of respondents in the 5-9 years category ranged from n=38 to n=111. The number of respondents in the 10-14 years category ranged from n=37 to n=73. The number of respondents in the 15-18 years category ranged from n=24 to n=38. The number of respondents in the 19+ category ranged from n=29 to n=39.

### Access to Healthcare Services

As described above, within healthcare, parents and caregivers responding to the community survey reported greatest difficulty accessing behavioral/mental health services, specialty care, and dental care. Data from the National Survey of Children's Health (NSCH) show that in 2022-2023, 31.8% of New Jersey children with special healthcare needs received care in a medical home, compared to 39.7% of children in the United States (Table 10).

**Table 10. Percent Children Aged 1-17 Who Received Care Within a Medical Home, by CSHCN Status, 2022-2023**

Geography	CSHCN	Non-CSHCN
United States	39.7%	46.8%
New Jersey	31.8%	44.1%

DATA SOURCE: National Survey of Children's Health, 2022-2023

NOTE: To qualify as having a Medical Home, children must meet the criteria for adequate care on the first three components: personal doctor or nurse, usual source for care, and family-centered care.

Data from the NSCH shows that a substantially higher proportion of families of children with special healthcare needs reported difficulties accessing specialist care in 2022–2023, both in New Jersey and nationally (Table 11). In New Jersey, 39.7% of parents of children with special healthcare needs reported difficulties, compared to 23.0% of other parents.

**Table 11. Percent Families Reporting Difficulties Obtaining Specialist Care, by CSHCN Status, 2022–2023**

Geography	CSHCN	Non-CSHCN
United States	39.0%	23.9%
New Jersey	39.7%	23.0%

DATA SOURCE: National Survey of Children's Health, 2022–2023

NOTE: Data shown combines responses "somewhat difficult", "very difficult", or "it was not possible to obtain care".

NOTE: CSHCN stands for Children with Special Healthcare Needs.

Quantitative data from the NSCH indicate that in 2022–2023, a higher proportion of children with special healthcare needs than other children received a preventative dental visit (Table 12). In 2022–2023, 88.9% of children with special healthcare needs in New Jersey had a dental check-up, compared to 77.8% of other children.

**Table 12. Percent Children Aged 1–17 Who Received a Preventive Dental Visit, by CSHCN Status, 2022–2023**

Geography	CSHCN	Non-CSHCN
United States	83.7%	77.9%
New Jersey	88.9%	77.8%

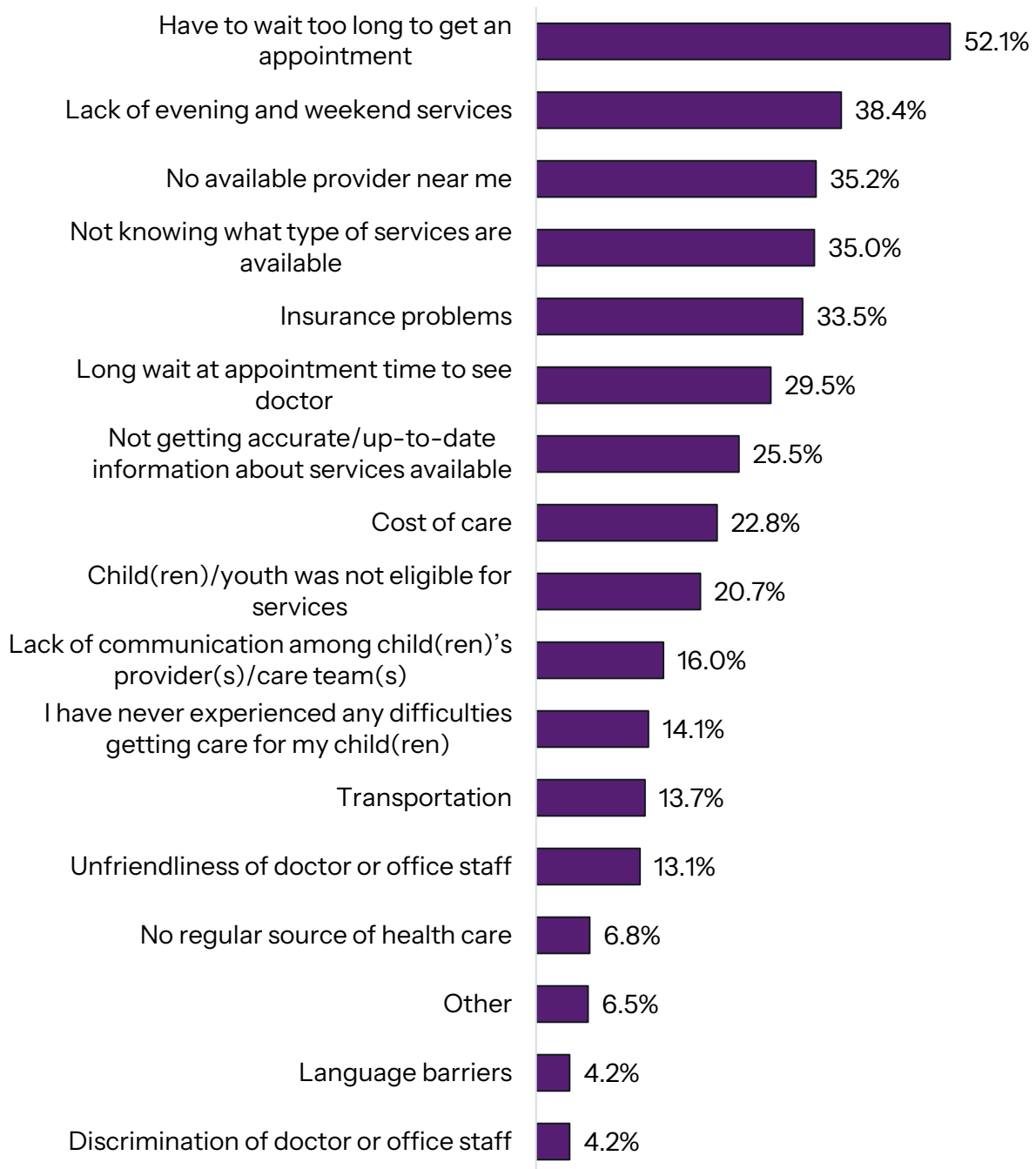
DATA SOURCE: National Survey of Children's Health, 2022–2023

NOTE: CSHCN stands for Children with Special Healthcare Needs.

### Barriers to Accessing Healthcare Services

When asked about challenges to accessing healthcare services, community survey respondents, interviewees and focus group members pointed to the same barriers including finding providers, getting appointments, insurance issues, and cost. Among top difficulties cited by parents/caregivers responding to the community survey were the ability to schedule appointments quickly (52.1%), lack of evening and weekend hours (38.4%), and lack of providers nearby (35.2%) (Figure 35). Far fewer respondents reported issues such as language barriers, no regular source of healthcare, or discrimination/ unfriendliness of providers' offices. In 2022, parent/caregiver respondents also identified the ability to schedule appointments quickly as the biggest barrier to accessing healthcare for their children with special healthcare needs, followed by not knowing what type of services are available and long wait time at appointment to see a doctor.

**Figure 35. Percent of Community Survey Respondents Reporting Issues that Make It Difficult to Access Healthcare for Children with Special Healthcare Needs, among Parents/Caregivers, n=474, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

As Table 13 shows, respondents from different racial/ethnic groups reported similar top challenges to accessing healthcare. Lack of evening and weekend hours, having to wait too long to get an appointment, and not knowing what type of services are available are among the top five challenges across groups. Respondents from all groups except Hispanic/Latino

respondents identified insurance problems as among top five challenges. Lack of providers nearby was a top challenge for Black non-Hispanic respondents, Asian non-Hispanic respondent and multi-racial non-Hispanic respondents.

**Table 13. Percent of Community Survey Respondents Reporting Issues That Make It Difficult to Access Healthcare for Their Children with Special Healthcare Needs, among Parents/Caregivers, by Race/Ethnicity, 2025**

	<b>Black, non-Hispanic (n=57)</b>	<b>Asian, non-Hispanic (n=22)</b>	<b>White, non-Hispanic (n=149)</b>	<b>Hispanic/Latino (n=102)</b>	<b>Other/2+ Races, non-Hispanic (n=14)</b>
<b>1</b>	Lack of evening and weekend services (40.4%)	Lack of evening and weekend services (50.0%)	Have to wait too long to get an appointment (62.4%)	Have to wait too long to get an appointment (56.9%)	No available provider near me (57.1%)
<b>2</b>	Have to wait too long to get an appointment (36.8%)	Have to wait too long to get an appointment (50.0%)	Lack of evening and weekend services (47.0%)	Lack of evening and weekend services (37.3%)	Lack of evening and weekend services (50.0%)
<b>3</b>	No available provider near me (33.3%)	Insurance problems (45.5%)	Not knowing what type of services are available (44.3%)	Not knowing what type of services are available (31.4%)	Have to wait too long to get an appointment (35.7%)
<b>4</b>	Insurance problems (31.6%)	Long wait at appointment time to see doctor (45.5%)	Insurance problems (43.6%)	No available provider near me (31.4%)	Not knowing what type of services are available (35.7%)
<b>5</b>	Not knowing what type of services are available (31.6%)	Not knowing what type of services are available (40.9%)	No available provider near me (43.0%)	Not getting accurate/up-to-date information about services available (29.4%)	Insurance problems (35.7%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

As shown in Table 14, parent/caregiver respondents with private insurance reported the same top challenges to accessing healthcare as those with public insurance.

**Table 14. Percent of Community Survey Respondents Reporting Issues that Make it Difficult to Access Healthcare for their Children with Special Healthcare Needs, among Parents/Caregivers, by Insurance Status, 2025**

	Private Insurance (n=171)	Government Insurance (n=161)
1	Have to wait too long to get an appointment (62.6%)	Have to wait too long to get an appointment (45.3%)
2	Lack of evening and weekend services (50.9%)	Lack of evening and weekend services (34.8%)
3	No available provider near me (42.1%)	Insurance problems (32.9%)
4	Not knowing what type of services are available (40.4%)	Not knowing what type of services are available (31.7%)
5	Insurance problems (38.0%)	No available provider near me (31.1%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

Interviewees and focus group participants, as well as comments shared by community survey respondents point, highlight some of the specific challenges families with children with special healthcare needs face when accessing healthcare services. These include finding providers, managing insurance, cost, and care coordination. These are discussed below.

#### *Finding Providers*

Lack of providers—across the healthcare spectrum but especially among therapies, developmental pediatrics, and dental and mental health—was a frequently-mentioned challenge. Participants noted an overall provider shortage, and several shared that they have had to wait many months,

*“There’s a wealth of resources and information out there. There are a lot of guides. But then getting actual access to those services becomes impossible.”*  
– Interviewee

sometimes a year or more, for some appointments. One parent survey respondent explained: *“The issue we run into is that there is only one or two therapists that provide the specific service my child needs which results in a year long (or more) waiting list. This is only doing more damage to the child who is in need of the service now.”*

Several participants and survey respondents shared their difficulties getting an appointment with developmental pediatricians whose recommendations are key to accessing additional services. One interviewee stated, *“We waited over a year to have my child evaluated because we were told that only one doctor does the evaluations and that is how long the wait list is. If he was evaluated sooner, he could have received services sooner.”*

Finding providers with expertise serving special needs patients is also a barrier. While CSH has an extensive and skilled workforce to meet the needs of patients with special healthcare needs, participants reported that providers outside this system have far less expertise. Parents of young adults and young adults with special needs talked about the challenges

they face in finding adult providers who have any experience working with special needs patients including exam rooms able to accommodate people in wheelchairs or that have adjustable exam tables. Particularly difficult, participants reported, is finding specialty healthcare providers who have this experience. Challenges finding mental health providers who can work effectively with special needs children and youth was discussed earlier in this report. Focus group participants and survey respondents noted similar barriers when accessing dental care. They reported that few dental providers are willing or have expertise to work with special needs patients, who often have unique sensory issues.

*"It's hard to find a dentist who understands that you need certain accommodations, like extra time and breaks as needed."*

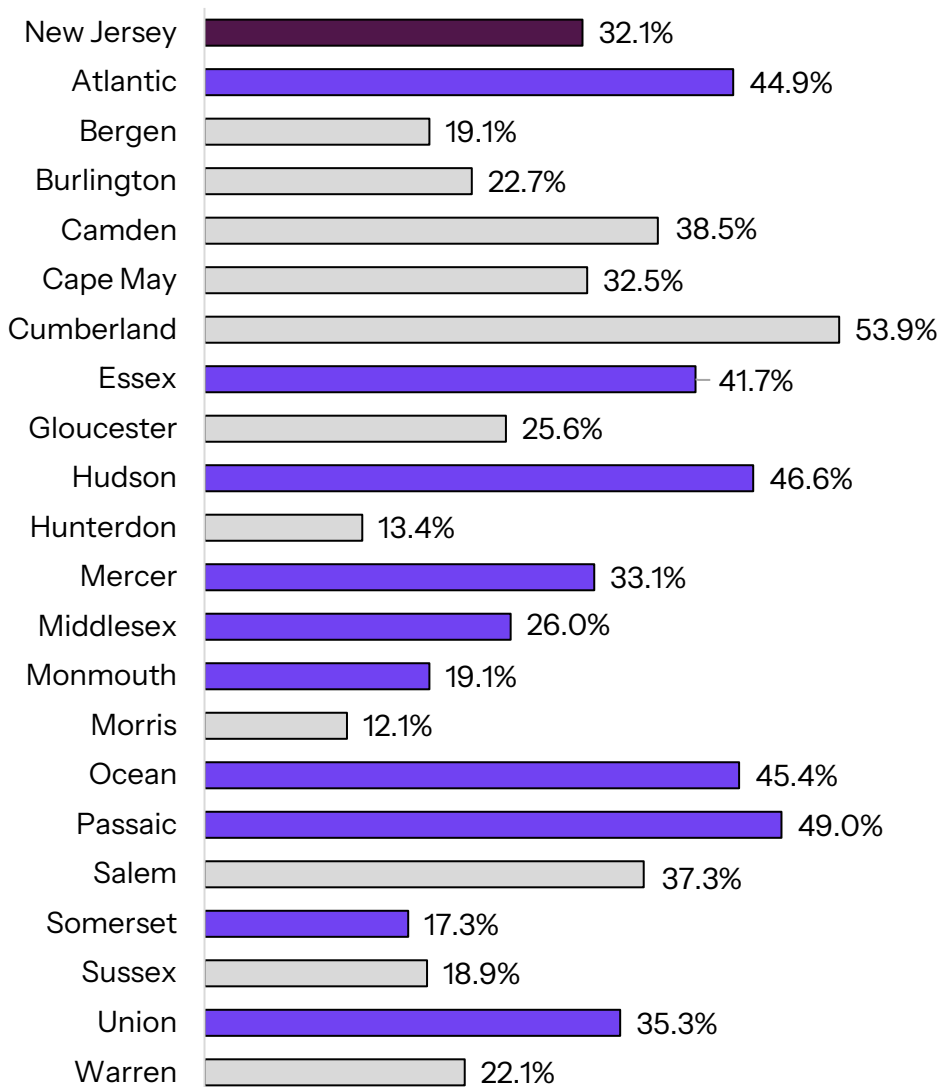
- Young adult survey respondent

#### Insurance Acceptance and Coverage

As with survey respondents, parent focus group participants and interviewees mentioned health insurance as a barrier to accessing healthcare for special needs children. They reported that finding providers who accept Medicaid is increasingly difficult as many providers, particularly specialists such as mental health professionals and dentists, no longer accept any insurance. Several of those who have relied on insurance to access therapy or mental health services for their children also reported that the number of sessions covered by insurance is sometimes limited, leading to gaps in access. However, one interviewee who works with families stressed that families are sometimes not aware of what insurance does cover; this person stated that many families do not know, for example, that Medicaid offers the Personal Preference Program (PPP), which enables disabled children and adults to remain in their homes by compensating family members for providing care.

According to American Community Survey data, in 2019–2023, 32.1% of children under age 19 in New Jersey were enrolled in Medicaid (Figure 36). The proportion of children under 19 enrolled in Medicaid is above the state average in seven of the counties with CSH locations (Atlantic, Essex, Hudson, Mercer, Ocean, Passaic, and Union). According to the 2022–2023 National Survey of Children's Health 35.4% of children in New Jersey with special healthcare needs ages 1–17 are enrolled in public health insurance, compared to 24.0% of other children (Table 15).

**Figure 36. Percent Children Enrolled in Medicaid, by State and County, 2019-2023**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2019-2023

**Table 15. Percent Children Aged 1-17 Enrolled in Public Health Insurance, by CSHCN Status, 2022-2023**

Geography	CSHCN	Non-CSHCN
United States	36.4%	27.8%
New Jersey	35.4%	24.0%

DATA SOURCE: National Survey of Children's Health, 2022-2023

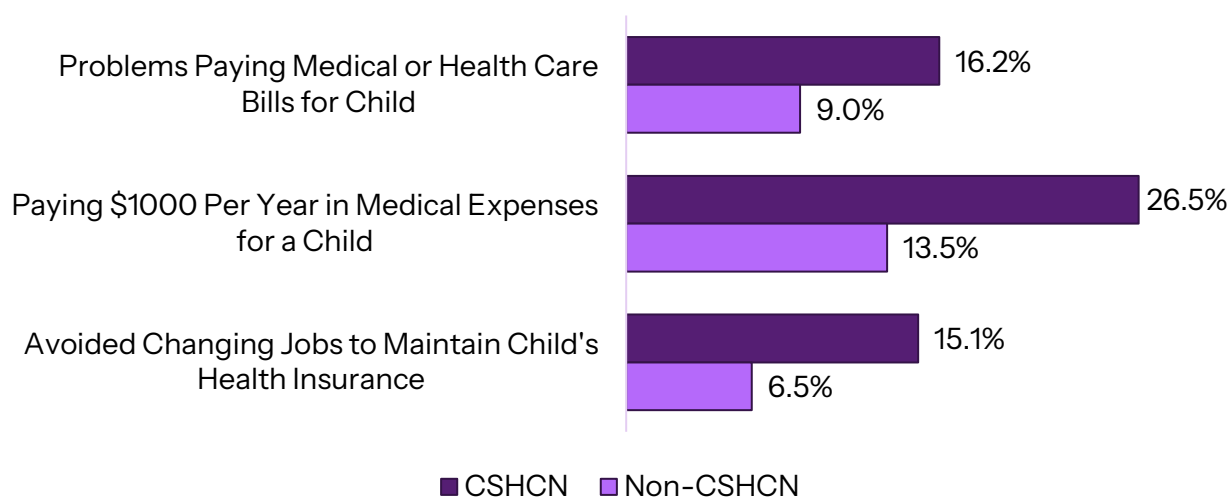
NOTE: This includes children enrolled in public health insurance only and enrolled in combination with private health insurance.

NOTE: CSHCN stands for Children with Special Healthcare Needs.

### Cost

The National Survey of Children's Health provides a quantitative picture of the financial challenges for families with special needs children. In 2022-2023, a far higher proportion of families with children with special healthcare needs reported problems paying medical or healthcare bills and paying over \$1,000 in medical expenses for their children, compared to other families (Figure 37). The proportion of families reporting that they paid more than \$1,000 a year in medical expenses for their child was twice as high as for other families, 26.5% compared to 13.5%. The proportion of families reporting problems paying medical or healthcare bills for their child was also much higher (16.2%) for families with special needs children than for other families (9.0%). Additionally, 15.1% of parents of special needs children reported that they had avoided changing jobs to maintain their child's health insurance, compared to 6.5% for other families. The proportion of families with special needs children reporting that their children's conditions caused family members to cut back or stop working was four times higher (24.6%) than for other families (5.9%).

**Figure 37. Percent Families Reporting Financial Challenges, by CSHCN Status, by State, 2022-2023**



DATA SOURCE: National Survey of Children's Health, 2022-2023

NOTE: CSHCN stands for Children with Special Healthcare Needs

Interviewees shared concerns about cuts and potential cuts to public funding that supports special needs children and their families. They shared examples of state budget challenges that have affected services including those provided at schools and the Arc of New Jersey services. Several expressed concerns about the future of Medicaid funding which affects healthcare as well as general support for lower income families. One interviewee stated, *"New Jersey is one of the few states that our Medicaid system covers so many things, healthcare being the biggest part but also early intervention and mental health services and development disability services for adults and all those things. So I think there's a lot more concern than there ever was [about Medicaid funding]."*

### Care Coordination

The systems serving children, youth, and young adults with special healthcare needs are complex, each having their own eligibility requirements, application processes, and coordinating organizations. Parents/caregivers and interviewees reported that navigating these systems and ensuring that their children's needs are addressed is very challenging.

While many organizations and agencies share information about different services and programs with parents/caregivers, there is no single coordinating entity to help them comprehensively identify and access the services that will work best for their children and their families.

*"There is a lot of opportunity for referrals, but not enough opportunity for warm handoffs and actually helping support connections."*

- Interviewee

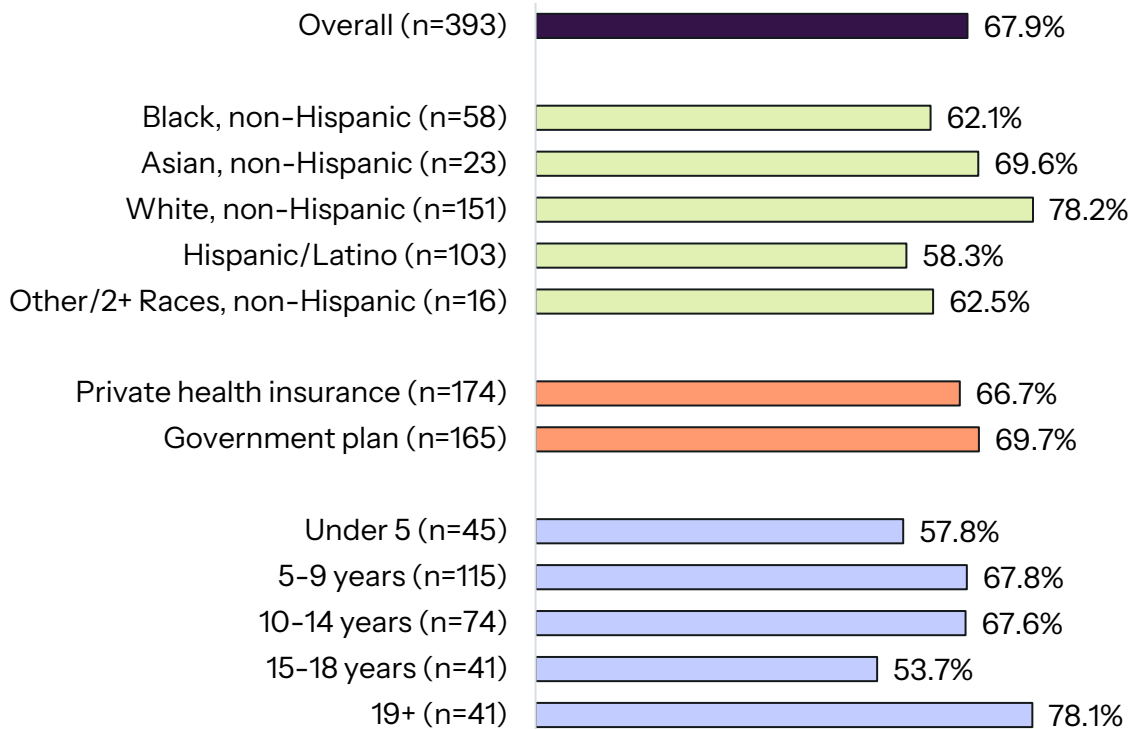
Parents/caregivers thus become responsible for coordinating these and translating between systems and professionals in their lives. Interviewees observed that parents/caregivers who face barriers such as language, time, or literacy are less likely to be able to effectively play this role. While care coordinators and case managers are available through the System of Care and in schools, participants noted that the expertise of staff in these positions varies, and turnover is high.

### **Use and Perceptions of Telehealth**

The COVID-19 pandemic accelerated the adoption of telehealth to deliver medical services. Experiences with and thoughts about telehealth varied among parents and caregivers responding to the community survey.

Figure 38 provides data from parent/caregiver survey respondents relative to use of telehealth. Overall, 67.9% of community survey respondents reported that they used telehealth to access medical care for their child with special healthcare needs at least once. While over half of survey respondents across all racial/ethnic groups reported that they have used telehealth, over three quarters of White, non-Hispanic respondents reported doing so, the highest proportion across all groups. There was little difference in use of telehealth by insurance status. Parents/caregivers of young children were least likely to report using telehealth to access healthcare for their special needs children while parents/caregivers of young adults were most likely to report using telehealth.

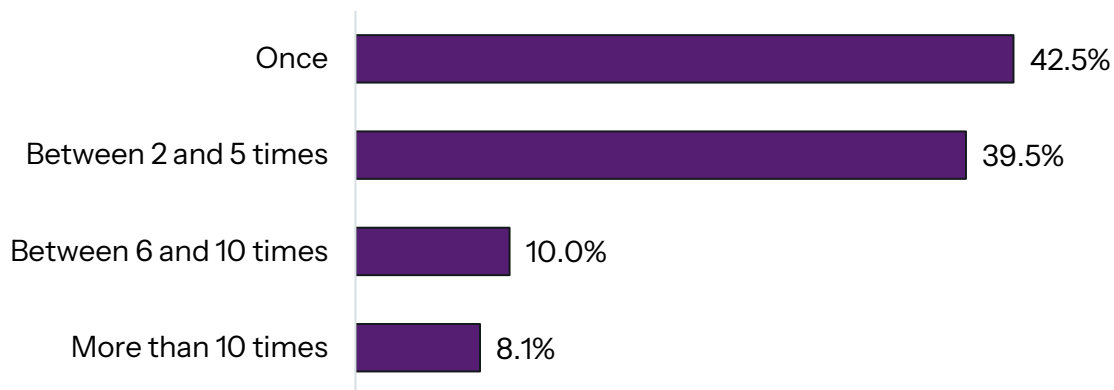
**Figure 38. Percent of Community Survey Respondents Indicating That They Have Used Telehealth, among Parents/Caregivers, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

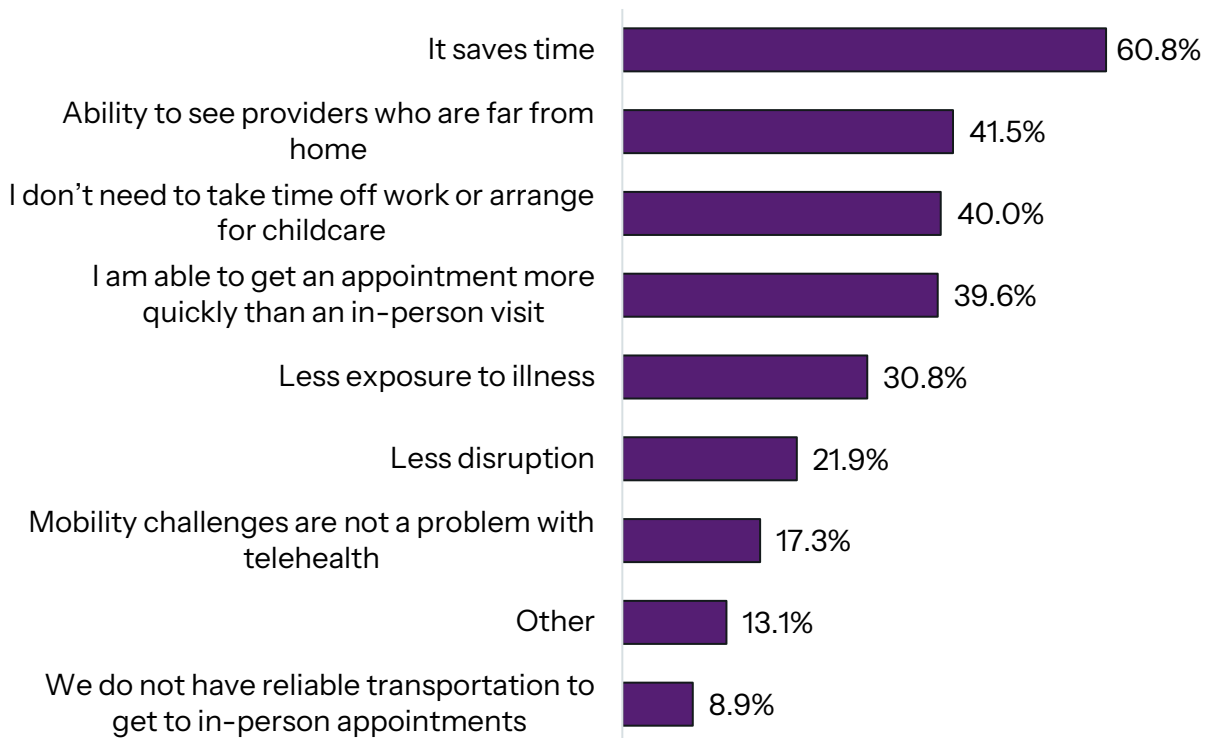
As shown in the following graphs, among those survey respondents who used telehealth within the past 12 months, about one third reported using it between 2 and 5 times over the year, while about 40% reported using it only once over the same time period. The top reason for using telehealth among survey respondents was that it saves time over in-person visits. They also noted that telehealth is convenient; one survey respondent wrote, *“We live over an hour away and this prevents us from having to travel over an hour each way for appointments.”* Those who cited “other” as a reason for using telehealth most often stated that their providers requested a telehealth visit.

**Figure 39. Percent of Community Survey Respondents Reporting Frequency of Telehealth Use, among Parents/Caregivers, 2025 (n=261)**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

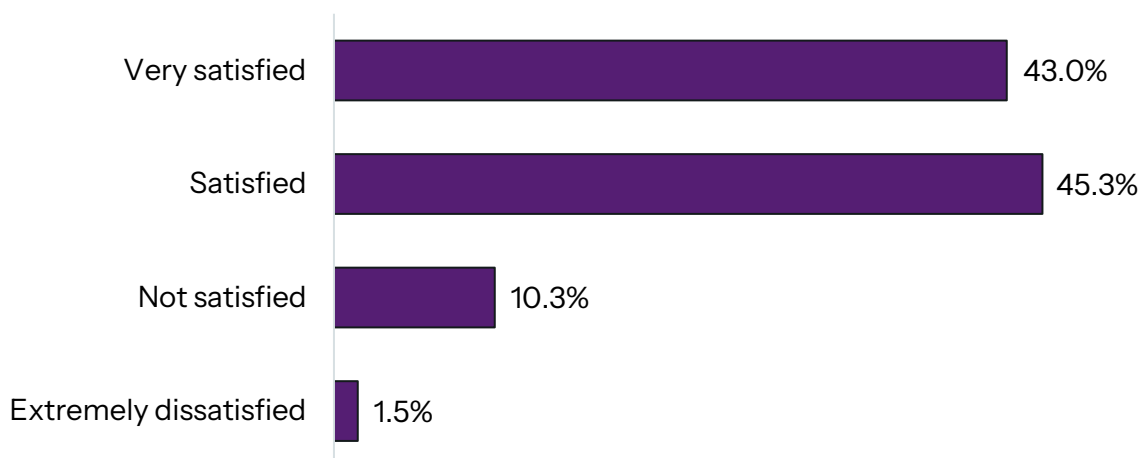
**Figure 40. Reasons for Telehealth Use, among Parents/Caregivers, 2025 (n=260)**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

Survey respondents who reported using telehealth generally expressed satisfaction with it: over 40% reported that they were very satisfied with it, while about 12% expressed some level of dissatisfaction (not satisfied or extremely dissatisfied) (Figure 41).

**Figure 41. Levels of Satisfaction with Telehealth Use, among Parents/Caregivers, 2025 (n=263)**

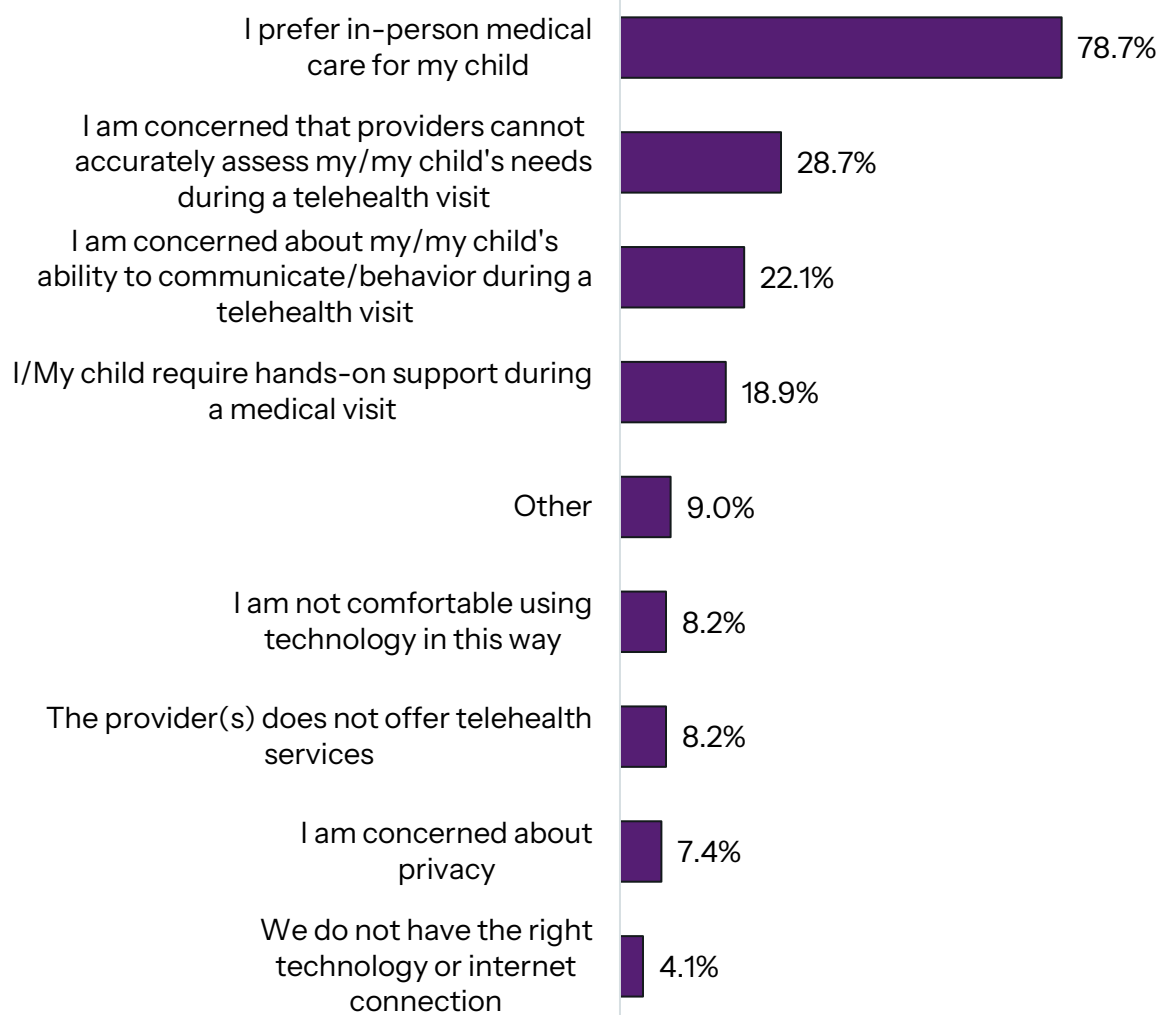


DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

Among survey respondents who have not used telehealth to access healthcare for their special needs child(ren), preference for in-person medical care was the reason most often

cited (Figure 42). Those who cited “other” as a reason for not using telehealth most often stated that telehealth was not an option offered by their providers.

**Figure 42. Reasons for Lack of Telehealth Use, among Parents/Caregivers, 2025 (n=126)**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

### Access to Services that Support Transition to Adulthood

The process of transitioning from school to adulthood was a frequent topic of conversation in interviews and in the parent focus group, and a prominent theme in the community survey. This period in a child’s life was described as an overwhelming time for parents with special needs children: they must plan and complete paperwork to move from youth to adult program services and benefits;

*“Families talk about it: they fall off a cliff. They’re with these pediatric or school systems for a long time. And it’s pretty consistent for the most part, what they’re able to access. And then everything changes over at the same time.”*  
– Interviewee

arrange for their children's pathway after school; and transfer their children from pediatric healthcare to adult providers.

One big change for families that comes with transition to adult services is moving to eligibility-driven systems; one interviewee explained: *"Education is an entitlement program. Children in special education, if they qualify, they're supposed to get the supports that they need. When we move into the adult system, it's all eligibility, and so they have to qualify for services."*

Parent focus group members, interviewees, and community survey respondents noted that existing services to support transition to adulthood are insufficient to meet the need. About half of parent/caregiver respondents to the CSH Community Survey indicated that services to support transition to adulthood are very hard or hard to access. About two-thirds of parents of youth ages 15–18 and parents of young adults over 19 reported that these services are very hard or hard to access. Challenges cited include planning for transition to adult services, accessing education and employment opportunities, finding adult healthcare providers, and availability of social and recreational programs and nursing and long-term care.

#### Planning for Transition to Adult Services

Planning is the first step on the journey to adulthood. While interviewees and parents stressed that thinking about adulthood should start early, in reality, this is challenging for many families who are already navigating the day-to-day challenges of life with an adolescent. Additionally, parents shared, it is often difficult to know where to begin. A survey respondent wrote: *"Navigating transition feels like you are traveling in a foreign country alone and you don't know the language. People point you in a direction, but you don't know what that means or what you are supposed to do when you get there."*

*"There should be a discussion as early as 14 and even sooner if it's appropriate. There should be a discussion about what life is going to look like after school. What are your goals and what kind of things do we need to put in place now, while you're still in like middle school, so that when you leave high school you can actually pursue some of those things."*

–Interviewee

Perspectives about the availability of information to support parents with planning for transition to adult services varied. Some participants reported that there is little information to help parents/caregivers understand what they need to consider, including information available in other languages. Other parents/caregivers, however, stated that information is available—for example through New Jersey's Disability Information Hub ([NJ.gov/disabilities](http://NJ.gov/disabilities)) and organizations such as the Boggs Center at Rutgers University, SPAN, and Arc of New Jersey—but wading through it and determining which resources are appropriate for a child's specific disabilities and needs is difficult. As one survey respondent wrote: *"There are timelines and checklists available, but these are insufficient when parents don't know what they don't know and don't know what to ask."* Similarly, several people noted that organizations sponsor workshops and webinars about planning for transition to adult services, but parents/caregivers often find it difficult to find the time to attend these.

### Employment and Post-Secondary Education

Another task for families of transition-age youth is identifying education and employment opportunities after their children leave the public education system. School districts, participants reported, prepare youth with special healthcare needs for adulthood by offering classes that build daily living skills and provide structured learning experiences (work-based learning) that expose students to job opportunities and get them involved in the community. However, the availability and quality of these experiences, parents report, varies across school districts and many are underfunded. *Many young people are connected to services provided by the Department of Vocational Rehabilitation Services (DVRs) which include coordination, support for college classes, job coaching, connection to jobs and internships and job support.* Yet, participants reported that some young people are not eligible for this support or are not aware of it. Sometimes, parents noted, there are waitlists for DVRs-sponsored jobs.

Parent focus group members also stressed the importance of finding the right employment fit as some jobs are not appropriate for the skill level of some special needs young adults. A couple of parents/caregivers of children who require minimal support in the workplace reported challenges finding appropriate employment programs. One parent shared, *“We are stuck right now. Her need is at once not enough and too much. She falls through the cracks. There is no specialized program that meets her needs.”* Participants in the parent focus group and community survey respondents frequently noted that parents/caregivers must often play an active role in helping their children with special healthcare needs find engaging things to do after graduating from high school. One focus group participant explained, *“Everything is on the parent. If we want our kids to get a job, then I’m going into Marshall’s and talking to the manager. If we want them to find them something to do, it’s on the parent, always on the parent.”*

*“It breaks my heart because we spend so much time and energy supporting these kids and students and trying to get them to this degree of ultimate independence and success, and then they graduate. And we’re just like, where’d they go? And they’re sitting home.”*  
-Interviewee

### Social and Recreational Programs

At the same time transition-age youth leave school—at age 18 or 21—they also often age out of the recreational and other programs that supported them and provided important social connections. Interviewees and parent/caregivers who responded to the survey and participated in the focus group stated that finding similar programs for young adults is challenging. One interviewee explained, *“Parents report (their transition-age children) are lonely. They don’t really do much. Everything is for kids. Everything is for under 18.”* While DVRs and day programs offered by the Division of Developmental Disabilities (DDD) provide social opportunities, these are limited to eligible young people. Participants reported that there are limited social and recreational programs for young adults with autism. A young adults survey respondent shared their experience, writing, *“Finding recreational activities that have people who have the same cognitive ability as me is very difficult.”* To address the lack of opportunities, an interviewee reported, some parents have started “homegrown”

programs to keep their young adults engaged with their peers and a few speech therapists have launched virtual or in-person social clubs for their young adult patients.

#### Transition to Adult Healthcare Systems

Numerous survey respondents and focus group participants shared the difficulties of moving their young adult children from pediatric to adult healthcare systems. Participants explained that parents/caregivers are often given a list

*“Finding primary care physicians who understand even the basics of my special needs is very difficult.”*  
–Young adult survey respondent

of adult providers from their pediatric provider or insurance, and must then call around to find someone accepting new patients. Finding a provider who has experience working with special needs patients is a challenge. One interviewee stated, *“You may have had a really great developmental pediatrician or pediatrician that understood disabilities. But the adult system doesn't seem to have that same level of care.”* A couple of focus group parents shared that their own primary care providers are now caring for their young adult special needs children.

#### Nursing and Long-Term Care

While not a prominent theme in conversations, a couple of parents and interviewees noted that some young adults with complex health issues will need long-term care and accessing this can be challenge. One interviewee reported that some young people and their families, *“Really struggle because the workforce is not there, even when we have increased nursing, families cannot find a nurse to staff their child 24 hours.”* While New Jersey's personal care benefit through Medicaid has enabled families to step in and serve as compensated caregivers to enable their children to live at home, there is still a need for and shortage of those who can provide skilled nursing care.

#### **Access to Other Services for Children with Special Healthcare Needs and their Families**

The following section describes the themes that emerged in conversations with interviewees and the focus group about access to other programs and services for children with special healthcare needs and their families. As described earlier, about half of community survey respondents identified recreational and support programs for special needs children and youth and programs for parents/caregivers and siblings as hard or very hard to access.

#### Programs for Children and Youth

Community-based programs—including sports programs, camps, and enrichment programs and support groups—enable special needs children and youth to socialize with others and have fun. However, many parents/caregivers find it hard to access these programs.

*“Community-based programs are so enriching – they give our loved ones a feeling of belonging and fulfillment. These programs provide potential peers that can last for life. So very important!! They are also important for the communities – who need to see DD/ID folks out and about and accept them more.”*  
–Community survey respondent

The primary barrier, according to parents/caregivers, is availability. While participants shared that some communities have numerous programs for special needs children and youth, others do not: communities in the southern part of the state, for example, tend to have fewer options than those in the northern tier. Some reported that while sports camps are plentiful, those that focus on arts, STEM, cooking or music are less so. Parents/caregivers described having to travel long distances to programs and camps. High quality programs, they explained, are often costly, have waitlists, or enroll large groups that don't work for some kids. Lack of transportation creates an additional barrier for some families.

Parents/caregivers also stated that it can be difficult to find programs suitable for their children's abilities—programs that provide enough support to enable them to thrive without being too difficult.

Perspectives on availability of different programs varied. Some people reported that programs for children and youth with autism are more plentiful than those for children and youth with physical mobility issues. Others, however, reported that it is harder to find programs for those with lower support needs. Staff turnover in programs is another challenge and one that can be especially distressing to special needs children and youth. One focus group parent explained, *"We find a lot of people coming and going, I don't think they pay the staff enough and that's a little upsetting because your kids grow very close to these people and they're basically dealing with very vulnerable people."*

*"It's hard to find programs where the staff understands how to engage with students w special needs and does so in ways that upholds their dignity. When a program is found, they tend to offer it for a shorter session, but the window of time that the program is offered tends to be shorter as well."*

–Survey Respondent

#### Programs and Supports for Families

According to the CSH community survey, 48% of respondents reported that programs and supports for parents/caregivers and siblings of special needs children and youth were hard or very hard to access. Interviewees and parent focus group participants shared a similar perspective. Parents described how they have benefitted from connecting with other parents of special needs children; one focus group parent explained, *"The biggest support comes from other parents. I've learned a lot from older parents with older children. I'm lucky I have that community with the older kiddos."* However, parent support groups are not located in all communities, and sometimes information about them is not well publicized.

Additionally, several participants stressed that parents/caregivers benefit most when they are in a group with others who share similar experiences. A parent shared, *"I found one group for parents and it only met twice. The extreme mix of disabilities within the group made it difficult for us to relate to each other."* In addition to learning from other parents,

*"Families with kids that have special needs are more isolated than the typical family. And so you have a situation where they're more isolated but on top of that their needs are greater. So it's a double whammy for them."*

–Interviewee

focus group participants and survey respondents shared that they have found educational webinars and information disseminated by statewide research and advocacy organizations to be very helpful.

Parents and interviewees also reported that there are few support groups for siblings of children with special needs and these can be very beneficial. A community survey respondent explained: *“Living with a person with special needs can be very stressful for many reasons. Children/siblings only know what they live and need opportunities to understand what is happening and to know that they are not alone.”* Several participants mentioned SibShops and related sibling programs offered by the Arc of New Jersey as one source of support for brothers and sisters but stated that these programs are limited and not available in all communities.

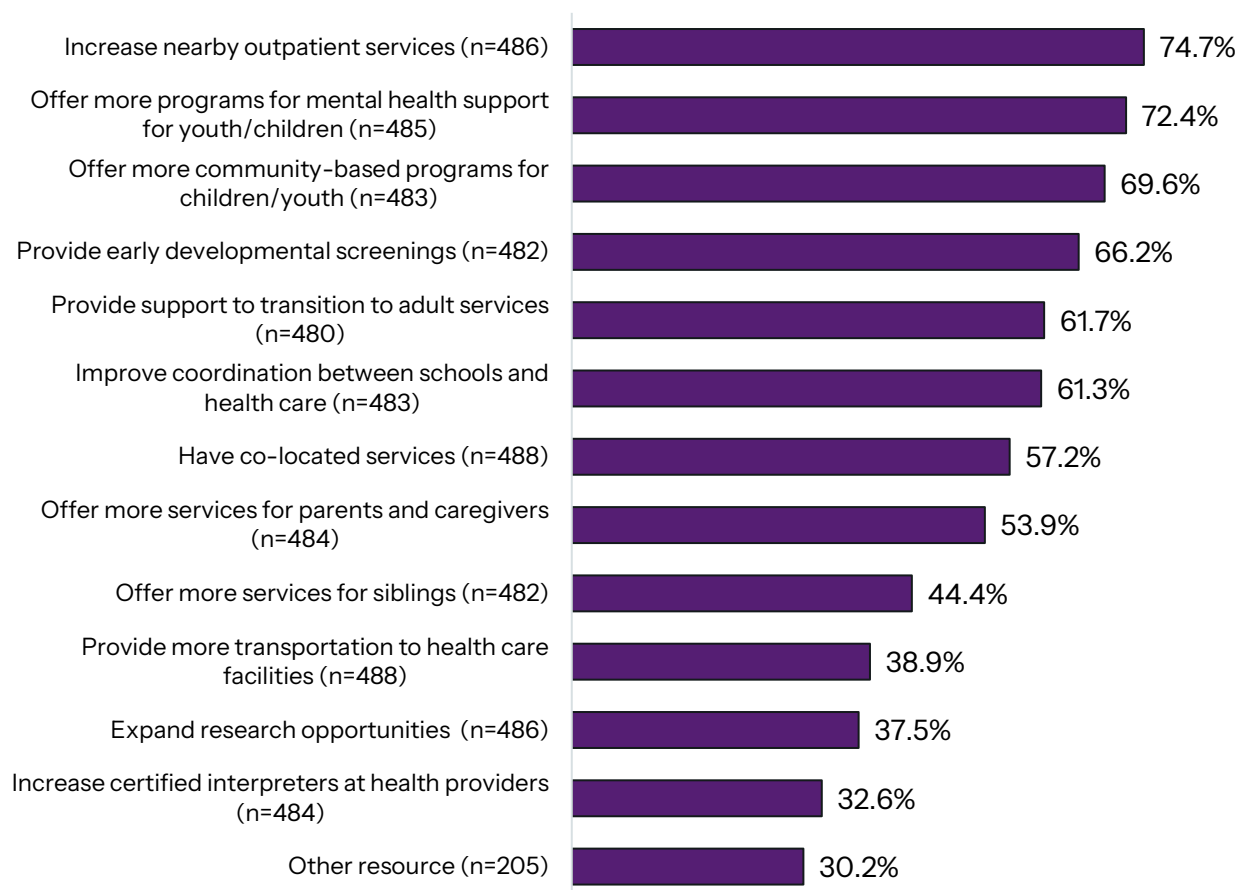
# Community Vision and Suggestions for the Future

Focus group and interview participants were asked for their suggestions for addressing the needs they identified relative to children and youth with special healthcare needs and their families. Community survey respondents were asked about service needs they believed were of high priority. The following section summarizes these recommendations.

## Community Survey Results

Survey respondents were asked which programs and services should be given low, medium, or high priority by facilities that serve children with special healthcare needs. Over three quarters rated outpatient services and mental health services as high priority, as shown below.

**Figure 43. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

In 2022, survey respondents identified these same two services as of highest priority. This year, nearly two-thirds of respondents rated community-based programs for children and youth and early developmental screenings as high priority (Table 16).

Services and programs rated as highest priority were largely similar between parent/caregiver respondents and other respondents. Both groups rated social, emotional, and other mental health services and outpatient services as highest priorities. Parent/caregiver respondents identified community-based programs for children/youth, early developmental screenings, and better coordination between schools and healthcare providers as next high priorities while other respondents identified transition to adult services, workshops for parents/caregivers, and transportation to healthcare as next high priorities.

**Table 16. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers and Other Respondents, 2025**

	Parents/Caregivers	Other Respondents
1	Increase nearby outpatient services (n=418) (80.4%)	Offer more programs for mental health support for youth/children (n=35) (66.7%)
2	Offer more programs for mental health support for youth/children (n=421) (76.5%)	Increase nearby outpatient services (n=34) (65.5%)
3	Offer more community-based programs for children/youth (n=441) (69.6%)	Transition to adult services (n=35) (65.5%)
4	Provide early developmental screenings (n=440) (68.4%)	Workshops for parents and caregivers (n=35) (60.3%)
5	Improve coordination between schools and healthcare providers (n=441) (62.8%)	Providing more transportation to and from healthcare facilities (n=35) (59.3%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

Survey respondents across all racial and ethnic groups identified mental health programs, community-based programs for children/youth and early developmental screenings among their top five priorities (Table 17). A higher proportion of Black and White, non-Hispanic parent/caregiver respondents identified transportation to healthcare as high priority, compared to respondents from other ethnic groups. Interpreters at health facilities were identified as high priority by Hispanic respondents while co-located services were identified as a high priority by Asian survey respondents.

**Table 17. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Race/Ethnicity, 2025**

	<b>Black, non-Hispanic</b>	<b>Asian, non-Hispanic</b>	<b>White, non-Hispanic</b>	<b>Hispanic/Latino</b>	<b>Other/2+ Races, non-Hispanic</b>
<b>1</b>	Offer more community-based programs for children/youth with special healthcare needs (74.1%)	Increase nearby outpatient services (90.0%)	Offer more programs for mental health support for youth/children with special healthcare needs (75.5%)	Offer more programs for mental health support for youth/children with special healthcare needs (76.8%)	Improve coordination between schools and healthcare providers (87.5%)
<b>2</b>	Offer more programs for mental health support for youth/children with special healthcare needs (70.4%)	Have co-located services (90.0%)	Offer more community-based programs for children/youth with special healthcare needs (68.2%)	Provide early developmental screenings (73.8%)	Offer more community-based programs for children/youth with special healthcare needs (81.3%)
<b>3</b>	Provide more transportation to healthcare facilities (69.4%)	Offer more community-based programs for children/youth with special healthcare needs (86.4%)	Provide early developmental screenings (64.0%)	Offer more community-based programs for children/youth with special healthcare needs (67.7%)	Provide early developmental screenings (80.0%)
<b>4</b>	Provide early developmental screenings (69.4%)	Offer more programs for mental health support for youth/children with special healthcare needs (85.0%)	Provide support to transition to adult services (63.6%)	Improve coordination between schools and healthcare providers (67.7%)	Offer more programs for mental health support for youth/children with special healthcare needs (75.0%)
<b>5</b>	Improve coordination between schools and healthcare providers (65.5%)	Provide early developmental screenings (77.3%)	Provide more transportation to healthcare facilities (61.0%)	Increase certified interpreters at health providers (61.7%)	Provide support to transition to adult services (73.3%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the Black, non-Hispanic category ranged from n=33 to n=58.

The number of respondents in the Asian, non-Hispanic category was n=22. The number of respondents in the White, non-Hispanic category ranged from n=150 to n=151. The number of respondents in the Hispanic/Latino category ranged from n=98 to n=100. The number of respondents in the Other/2+ Races, non-Hispanic category ranged from n=15 to n=16.

There was little difference in prioritized services between survey respondents with public insurance and those with private insurance (Table 18).

**Table 18. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Insurance Status, 2025**

	Private Insurance	Government Plan
<b>1</b>	Increase nearby outpatient services (83.1%)	Offer more programs for mental health support for youth/children with special healthcare needs (82.6%)
<b>2</b>	Offer more programs for mental health support for youth/children with special healthcare needs (72.0%)	Increase nearby outpatient services (80.7%)
<b>3</b>	Offer more community-based programs for children/youth with special healthcare needs (69.4%)	Offer more community-based programs for children/youth with special healthcare needs (70.6%)
<b>4</b>	Provide early developmental screenings (68.2%)	Provide early developmental screenings (69.2%)
<b>5</b>	Improve coordination between schools and healthcare providers (62.4%)	Have co-located services (67.1%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the private health insurance category ranged from n=120 to n=173. The number of respondents in the government plan category ranged from n=122 to n=160.

Increasing nearby outpatient services and more mental health services were identified as among the top five priorities for parents/caregivers of children/youth across all age groups (Table 19). Consistent with qualitative feedback, parents/caregivers of older youth rated community-based programs for children/youth with special healthcare needs as highest priority while parents of youth older than 19 rated support for transition to adult services as highest priority. Parents/caregivers of younger children identified greater access to early developmental screenings as among their top suggested priorities.

**Table 19. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Age of Child, 2025**

	Under 5	5-9 years	10-14 years	15-18 years	19+
<b>1</b>	Increase nearby outpatient services (88.1%)	Increase nearby outpatient services (85.6%)	Increase nearby outpatient services (72.9%)	Offer more community-based programs for children/youth with special healthcare needs (80.0%)	Provide support to transition to adult services (80.5%)
<b>2</b>	Offer more programs for mental health support for youth/children with special healthcare needs (76.9%)	Offer more community-based programs for children/youth with special healthcare needs (79.5%)	Offer more programs for mental health support for youth/children with special healthcare needs (68.6%)	Offer more programs for mental health support for youth/children with special healthcare needs (79.0%)	Offer more programs for mental health support for youth/children with special healthcare needs (72.5%)
<b>3</b>	Have co-located services (65.9%)	Provide early developmental screenings (79.3%)	Offer more community-based programs for children/youth with special healthcare needs (68.5%)	Increase nearby outpatient services (79.0%)	Increase nearby outpatient services (66.7%)
<b>4</b>	Provide early developmental screenings (62.2%)	Offer more programs for mental health support for youth/children with special healthcare needs (75.2%)	Provide early developmental screenings (57.5%)	Provide support to transition to adult services (72.5%)	Have co-located services (65.8%)
<b>5</b>	Increase certified interpreters at health providers (63.3%)	Improve coordination between schools and healthcare providers (74.1%)	Provide support to transition to adult services (54.2%)	Improve coordination between schools and healthcare providers (65.0%)	Offer more community-based programs for children/youth with special healthcare needs (63.4%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the Under 5 category ranged from n=32 to n=42. The number of respondents in the 5-9 years category ranged from n=84 to n=112. The number of respondents in the 10-14 years category ranged from n=73 to n=151. The number of respondents in the 15-18 years category ranged from n=29 to n=40. The number of respondents in the 19+category ranged from n=29 to n=41. The number of respondents in the multiple ages category ranged from n=49 to n=61.

## Suggestions for Future Consideration

### Healthcare Services

Focus group participants, interviewees, and survey respondents identified several gaps in healthcare services for children and youth with special healthcare needs. Suggestions to address these included:

- *Increasing availability of healthcare services.* Participants cited barriers to accessing healthcare for special needs children that include long waitlists for appointments, having to travel long distances to access care, and, increasingly, difficulty finding providers who accept Medicaid and other insurances (Figure 35). They reported the greatest difficulty finding therapists, developmental pediatricians, mental health providers, and dentists. Community survey respondents identified the need for outpatient services as highest priority (Figure 44). Addressing the workforce shortages that underlie barriers to healthcare access requires longer-term, multi-pronged, systemic approaches. More immediately, a couple of participants wondered whether there is an opportunity to collaborate with providers elsewhere in the RWJB Health system to expand access for families with special needs children, particularly for services like mental health and developmental pediatrics.
- *Expanding availability of developmental assessments.* Early diagnosis leads to earlier intervention for disabilities, and better outcomes. Currently, participants report long times for screening and assessments, both for young children and for students trying to access school-based supports. Early access to developmental screenings was identified as a high priority by CSH community survey respondents (Figure 44). Several people suggested holding free screening events in public spaces and at daycares. Interviewees, focus group participants, and survey respondents also identified a need to increase the number and types of providers able to conduct these assessments. One survey respondent suggested that there is “a wealth of masters-level school psychologists in the state with significant experience working with children with special needs” who could play this role after hours and with supervision. At the same time, participants recommended more training of pediatricians and family practice physicians so they can identify early developmental delays.
- *Enhancing provider expertise to work with special needs children and youth and their families.* Parent/caregivers described their challenges finding providers outside the CSH system who have experience working with special needs children and youth. For young adults transitioning to adult healthcare systems this is particularly difficult. While participants recognized that providers outside a specialized system cannot be experts in special needs healthcare, they did suggest that training and support to providers in other practices would improve quality of care and expand access for special needs patients. One interviewee recommended a consultative approach such as is currently used for child psychiatry through the New Jersey Pediatric Psychiatry Collaborative. Another interviewee suggested that CSH’s family faculty could lead “grand rounds” for providers across the system, similar to the University of Wisconsin School of Medicine’s Family-Led Academic Grand (FLAG) Rounds.

- *Strengthening communication and coordination between healthcare and schools.* Parents/caregivers spoke about challenges they faced navigating between school and healthcare systems to ensure their children received timely assessments that guided decisions about school-based supports. They recommended more support within healthcare systems, such as through an in-house social worker or case manager, to ensure that providers provide clear, timely, and actionable information for parents and school systems.

### Mental Health Services

Mental health concerns among young people with special healthcare needs and the need for more programs and services to support them were prevalent themes in the community survey, in the parent focus group discussion, and in interviews. A high proportion of survey respondents identified social, emotional, and other mental health services as “high priority” (Figure 44). The barriers to accessing mental health services are significant and include shortage of mental health providers, few providers willing to accept Medicaid and other insurances, and lack of provider experience with special needs children and youth all contribute to access challenges. Participants suggested:

- *Expanding mental health services.* Participants recognized that a significant constraint on mental health services stems from workforce shortages and wondered whether enhancing the role of other professionals could address some gaps. When asked about prioritizing specific mental health services, about 60% of community survey respondents reported that increasing mental health evaluations/services from providers other than physicians (Advanced Practice Nurses, Licensed Clinical Social Workers, etc.) should be high priority.
- *Enhancing mental health provider expertise to work with special needs patients.* Noting that it is important for mental health providers working with special needs children and youth to be able to distinguish behavioral issues associated with a neural development diagnosis from those deriving from a mental health condition, several participants suggested expanded education and support for mental health providers. Recommendations included training and the use of a consultative model (described above in the health services section).

### Transition to Adult Services

Over half of CSH community survey respondents reported that services to support transition to adulthood are hard or very hard to access (Figure 34); over 60% said that increasing these should be high priority (Figure 44). Interviewees and focus group participants with special needs children spoke about the challenges associated with planning for and moving to eligibility-based systems, finding post-secondary education and employment opportunities, connecting with adult healthcare providers, and keeping their young adult children engaged through recreational and social activities. To address these gaps, participants suggested:

- *Providing more information to support planning for transition to adulthood.* Given the importance of starting to plan for transition to adult services many years prior to high school graduation, numerous participants suggested more should be done to educate parents about the importance of planning ahead and to provide them with specific and actionable information about how to do so. They saw healthcare providers as

important messengers. One interviewee suggested, *“Maybe once a year during the annual visit, after age 14 up until transition, the doctor can ask ‘What have you been doing about transition to adult services planning. Are you familiar with this, this, or that? And here’s information.’”* Suggestions also included workshops and presentations that walk parents through eligibility requirements and the steps for application to benefits and programs such as Supplemental Security Income (SSI) and those offered through DVRS and DDD. Several participants argued for care coordinators to support the transition to adult services—professionals with comprehensive understanding of the many services and programs available to special needs young adults, including transportation and housing, and who can guide families through decision-making and application.

- *Expanding work opportunities and job supports.* A theme in many conversations about challenges related to transition to adult services was difficulty identifying and accessing education and job opportunities. Participants advocated for more opportunities that expose young adults with special needs to job and volunteer opportunities during high school and after, as well as more information about post-high school employment opportunities. Several parent focus group participants suggested that CSH consider whether and how it might create volunteer or paid opportunities within the hospital for young adults with special needs, such as being a greeter, handing out visitor passes, or serving as a therapy aide.
- *Building adult skill building into existing services.* Interviewees and focus group members saw an opportunity to rethink existing OT, PT, and speech services for older adolescents to incorporate job skills training. For example, a parent pointed out that a wheelchair-bound young person in occupational therapy could learn to deliver things using their chair which could be helpful for employment. One parent observed, *“If you had more meaningful goals [in therapy] then maybe [my child] could get a job because he’s been practicing these kinds of skills. I wish therapy could be more job driven.”* An interviewee suggested that the functionally-focused OT services at Kean University’s Community Cares Clinic could be a potential model. Parents also described leadership opportunities, such as serving on youth boards, as a way for adolescents and young adults with special needs to build job skills. One parent shared her child’s experience representing CSH in the community: *“Speaking about his disability in the community gave him a lot of strength to talk to people when he went into the adult world to do interviews.”*
- *Increase socialization programs for young adults.* As described earlier, parents participating in focus groups and in the community survey greatly value opportunities for their children to socialize with others. However, young adults often age out of these experiences. Parents/caregivers as well as young adults reported that they would like to see more organizations provide social and recreational opportunities specifically for special needs young adults and ideally, offer transportation so young adults can access them independently.

- *Expanding residential placement options.* While not a prominent theme in the survey or in the focus group discussion, a couple of interviewees stated that as the population is aging, there will be a growing need for community living, residential placement, and day programs for special needs adults as well as the nursing staff necessary to provide care.

### Programming for Children and Youth

Community survey respondents, interviewees, and focus group participants all saw a need for more programs that enable special needs children to socialize with others and learn new skills. Over half of survey respondents indicated that these programs are currently hard or very hard to access (Figure 34) and about 70% reported that expanding these types of programs should be high priority (Figure 44).

- *Increasing programs.* Participants recommended more sports programs, summer camps, and afterschool and community programs that offer arts, music, and education. A few suggested expansion of safe, affordable outdoor spaces like CSH's Field of Dreams. Others spoke about the benefits of CSH's Activity Connection for their children and recommended that this program be expanded because slots fill up quickly. Some people advocated for programs and services that are inclusive of children and youth with range of abilities. Others argued for a diversity of programs to meet the needs of different children and youth. Addressing affordability of these programs through scholarships and sliding scale fees was also recommended.

### Supports for Families

Supporting families of children with special healthcare needs was a frequent topic of conversation in interviews and the parent focus group; about half of survey respondents identified these types of programs as "high priority." Recommendations included:

- *Increasing Parent Education and Support Groups.* Parents/caregivers would like more opportunities for education, either in person or virtually. Suggested topics included understanding diagnoses, navigating systems, ADHD, planning for transition to adult services, and positive relationships as children get older. Several people stressed the need for focused education delivered by experts that addresses parents' specific questions and concerns, rather than more broadly-focused information that is already provided by other organizations. Having information available in multiple languages and in different formats is also critical. One person suggested providing "bite-sized" information through an app. Another suggested engaging CSH therapists working in schools to identify the types of information that would be most useful to parents and how to best reach them. Noting the value of talking to and learning from other parents, focus group participants and survey respondents would also like more support groups, both in person and virtual. As one interviewee observed, "*Parents are so separated and really need an opportunity to come together and discuss these issues. And starting those conversations very early on.*" To be of greatest value, they suggested, groups should bring together parents/caregivers whose children have similar diagnoses and should be professionally facilitated.
- *Providing Support for Siblings.* Parents/caregivers also recommended more programs and groups to help brothers and sisters learn coping skills related to living

with a special needs sibling and have an opportunity to talk about their feelings and ask questions. As one survey respondent wrote, *“Siblings need to know they are not the only one struggling with sibling care. They need support to show them they are important too, and the entire family dynamic is not only about the child with special healthcare needs.”*

### Social Determinants of Health

Upstream factors—financial stability, education and employment, access to healthy food, reliable transportation and safe housing—all play a role in advancing good health and helping families meet the needs of their children with special healthcare needs. Secondary data indicate that families with special needs children face greater financial challenges than other families (Figure 37). Secondary data and CSH community survey results indicate that food insecurity is a challenge for a number of community families with special needs children (Figure 18) and CSH patient families.

- *Expanding food and transportation support.* While food needs were not explicitly discussed in interviews or the focus group, participants did note that financial pressures facing some families with special needs children and youth made it more difficult for these families to make ends meet. Finally, transportation barriers play a role in hindering access to healthcare for some families with special needs children and young adults with special needs who want to access employment and education opportunities as well as social and recreational programs. A few participants suggested that health providers expand the transportation options they provide, including for outpatient therapies. Other suggestions included meeting transportation needs of patients by providing gas cards and vouchers for taxis and ride services.

# Key Themes and Conclusions

Through a review of secondary social and economic data, a community survey, and discussions with parents, young people with special healthcare needs, and stakeholders, this assessment report examines the current health status of special needs children in New Jersey. Several overarching themes emerged from this synthesis:

- ***New Jersey has many assets for children and youth with special healthcare needs and their families; however, there are barriers to accessing these.*** New Jersey's many resources to support children with special healthcare needs and their families include specialty hospitals and other healthcare services, community-based programs that offer sports and socialization opportunities, and statewide organizations that advocate for and educate parents and caregivers. Assessment participants noted that unequal distribution of these across the state, as well as lack of awareness of them, are barriers to access. Families with special needs children seeking health services face challenges such as too few providers, long wait times for appointments, lack of evening and weekend hours, limits on insurance coverage, and a growing number of providers who do not accept Medicaid. Particularly challenging are finding therapists, developmental pediatricians, and mental health and dental providers. Limited provider experience working with children and youth with special healthcare needs is also a concern as this negatively affects quality of care and health outcomes. Recreational, sports, and peer socialization programs, as well as programs and support groups for parents and caregivers, are often far from home, have limited enrollments, and are costly.
- ***Increasing access to key health services, including mental health services, is a priority.*** Assessment participants cited a need for more outpatient services such as OT, PT and speech, mental health services, and early developmental screenings. Addressing workforce shortages underlying healthcare access requires systemic solutions. More immediately, participants suggested collaborating with existing providers elsewhere in the RWJB health system to expand care for special needs children and youth, including providing support to these providers to enhance their expertise and comfort level working with children with special healthcare needs. Addressing the mental health and social emotional needs of special needs children and youth was identified as a high priority by assessment participants. They cited a need for more mental health providers, which they suggested could be addressed in part by enhancing the roles of other professionals, such as nurses and social workers, to provide these services. Given the importance of assessment to ensure children with special healthcare needs are connected to needed services, expanding the workforce of professionals able to conduct these assessments was also suggested.
- ***Participants see a need for more programs that support preparation for adulthood.*** Moving from pediatric to adult services is an overwhelming time for parents with special needs children and requires planning and support. Assessment participants noted that parents/caregivers could benefit from more information and support related to the specific steps they need to take to support their child on the pathway to adulthood. They suggested that pediatric providers could play a role in this. Parents and young adults advocated for more work opportunities and job support, as well as for better

incorporation of employment skill building into occupational and speech therapies provided in late adolescence. Increasing recreational and social opportunities as well as leadership skill building for young adults with special needs was also seen as critical to successful adulthood.

- ***Participants would like to see more social and recreational programs for children with special healthcare needs, and support for their parents, caregivers, and siblings.*** Assessment participants requested more sports programs, summer camps, and afterschool and community programs that offer arts, music, and education to enable special needs children and youth to develop skills and socialize with their peers. Many also noted that parents/caregivers and siblings of children with special healthcare needs could benefit from additional educational and emotional support, including workshops and support groups. Addressing barriers such as transportation, language, and cost is also important.
- ***Addressing social factors that affect health and access to healthcare should be considered.*** Information from this assessment point to greater financial challenges for families with special needs children. Some families also experience transportation barriers and food insecurity. Young adults reported that they have difficulty accessing transportation which affects their ability to access employment and education opportunities as well as social and recreational programs. Assessment participants suggested expansion of existing transportation options, especially for medical appointments, through hospital-provided transportation or mechanisms for reimbursement for use with public transportation and car services.

# Prioritization and Alignment

Prioritization allows hospitals and their partner organizations and coalitions to target and align resources, leverage efforts, and focus on achievable objectives and strategies for addressing priority community health needs. Priorities for this process were identified by examining data and themes from the CHNA findings utilizing a systematic, participatory approach. This section describes the approach and outcomes of the prioritization process.

## Criteria for Prioritization

The prioritization criteria used by the CSH Advisory Committee to refine the priorities included the following, which have been approved by the RWJBH System Steering Committee prior to data gathering and planning:

- **Burden:** How much does this issue affect our community?
- **Equity:** Will addressing this issue substantially benefit those most in need? Does this issue address the root causes of inequities?
- **Impact:** Can working on this issue achieve both short-term and long-term changes? Is there an opportunity to enhance access/ accessibility?
- **Systems Change:** Is there an opportunity to focus on/ implement strategies that address policy, systems, and environmental change?
- **Feasibility:** Is it possible to take steps to address this issue given current infrastructure, capacity, and political will?
- **Collaboration/Critical Mass:** Are there existing groups across sectors already working on or willing to work on this issue together?
- **Significance to Community:** Was this issue identified as a top need by a significant number of community members?

## Prioritization Process

The prioritization process was multifaceted and aimed to be inclusive, participatory, and data driven. During each step of the primary data collection phase of the CHNA, assessment participants were asked for input. Interviewees and focus group participants were asked about the most pressing concerns in their communities and areas for future action (Appendices B and C). Community survey respondents were also asked to identify high priority areas for action, noted in the Community Vision and Suggestions for the Future section of this report.

Based on responses gathered from key informant interviews, focus group participants, and community survey respondents, as well as social, economic, and health data from surveillance systems, eight major initial issue areas were identified for the CSH service area:

- Access to adult services
- Access to healthcare services
- Educational access and special education needs
- Financial insecurity
- Food insecurity
- Mental health and social emotional development
- Overweight/obesity
- Transportation

These findings were then presented and discussed in a two-step prioritization process.

*Step 1: Data-Informed Voting via a Preliminary Polling Process-*

On June 2, 2025, a 90-minute virtual Key Findings Presentation and Polling meeting was held with the CSH Advisory Committee to present and discuss the preliminary findings and conduct a poll to identify potential themes for the hospital to address.

During the meeting, attendees heard a brief data presentation on the preliminary key findings from the assessment. Next, meeting participants were asked the following discussion question: Do these findings reflect what you see among children, families, and parents? A group discussion ensued where participants reflected on the data shared and offered their perspectives and feedback on the various issues. Then, using the polling platform Mentimeter, meeting participants were asked to choose their top four key health issues identified from the data based on how well each health issue met the RWJB system-wide criteria. Preliminary polling results identified the following four issues: mental health and social-emotional development, access to healthcare services, access to services that support transition to adulthood, and educational access and special education needs.

*Step 2: CSH Leadership Refinement of Priorities*

The CSH Leadership team met to review the polling results from the Key Findings Presentation and Polling meeting and to further discuss and refine the priorities for the CSH Implementation plan. HRiA met with CSH's project team to discuss the feedback from the CSH Leadership team and to refine final priority area titles for planning.

**Priorities Selected for Planning**

Based on the assessment findings as well as existing initiatives, expertise, capacity, and experience CSH selected the following priorities to focus on when developing their implementation plan: Food Insecurity; Access to Healthcare Services; Transition to Adult Services; and Mental Health and Social Emotional Development.

It is noted that the needs prioritized and selected by CSH for improvement planning are in line with the New Jersey State Health Improvement Plan 2020 which addresses strategies for improvement Health Equity, Mental Health/Substance Use, Nutrition, Physical Activity and Chronic Disease (additional focus areas included Birth Outcomes, Immunizations and Alignment of State and Community Health Improvement Planning.) Further, actions for the prioritized needs support the four, broad Health New Jersey 2030 topic areas that represent the key elements that influence health:

- 1) Access to Quality Care
- 2) Healthy Communities
- 3) Health Families
- 4) Healthy Living

In 2025, CSH will bring together stakeholders and subject matter experts for a planning process and the development of an implementation plan that identifies goals and strategies for addressing the CSH priorities: Food Insecurity; Access to Healthcare Services; Transition to Adult Services; and Mental Health and Social Emotional Development.

# Appendices

## **Appendix A: Organizations Represented in Key Informant Interviewees and Focus Groups**

Arc of New Jersey

Barger and Gaines

BOGGS Center on Developmental Disabilities

Children's Specialized Hospital Family Advisory Council

Children's Specialized Hospital Family Faculty

Children's Specialized Hospital School Services

Dover Public Schools

New Jersey Department of Human Services

Special Education Parent Advisory Group (SEPAG)

Statewide Parent Advocacy Network (SPAN)

Union County Educational Services Commission

## Appendix B: Key Informant Interview Guide

### Goals of the interview

- To determine interviewees' perceptions of the most pressing health and healthcare issues for children with special healthcare needs and their families
- To identify the gaps, challenges, and opportunities for addressing community needs more effectively

### BACKGROUND (5 minutes)

- Hello, my name is \_\_\_\_\_ and I am with Health Resources in Action, a non-profit public health organization. We have been hired by Children's Specialized Hospital to support their community health needs assessment. Thank you for taking the time to speak with me today.
- Children's Specialized Hospital is conducting a community health assessment to gain a greater understanding of the needs of children and youth with special healthcare needs and their families, how those needs are currently being addressed, and whether there might be opportunities to address these issues more effectively.
- We are conducting several interviews and will also be conducting focus groups with transition-age youth and community-based professionals who work with children and youth with special healthcare needs. We greatly appreciate your feedback, insight, and honesty.
- Our interview will last about 45-60 minutes. After all the data gathering is completed, HRiA will summarize the key themes that have emerged during these discussions. HRiA will be including quotes, but will not include any names or identifying information.
- [NOTE IF TRANSCRIBING] We plan to transcribe these conversations just to ensure we have captured the main points of the discussion in case there are any interruptions in the note-taking. No one but the analysts at Health Resources in Action, who are writing the report, will be reviewing the transcription. Do you have any concerns with me turning on the transcription now?

Do you have any questions before we begin?

### PARTICIPANT ORGANIZATION / AGENCY (5 minutes)

#### 1. Can you tell me a bit about your organization/agency/work?

[FOR ORGANIZATIONS]

- a. What type of programs/services do you provide?
- b. Which geographic area(s) do you serve?
- c. Who are the main clients/audiences for your programs?
- d. Has your organization ever partnered with Children's Specialized? If so, in what capacity?

[FOR NON-ORGANIZATIONS/PROVIDERS]

- a. What type of services do you provide?
- b. Who are your clients?
- c. [FOR NON-CSH AFFILIATED] Have you ever partnered with Children's Specialized? If so, in what capacity?

### **CONCERNS AND BARRIERS (20 minutes)**

2. What are some of its biggest day-to-day concerns for children with special healthcare needs and their families in New Jersey? [PROBE ON SPECIFIC POPULATIONS: Transition-age youth]
3. What barriers do families face in addressing these concerns?
  - a. Are some families facing these barriers more than others?
4. What do you think are the most pressing health concerns for children with special healthcare needs and their families?  
[IF NOT BROUGHT UP, PROBE: transition to adult services]
5. From your experience, what barriers do families face in addressing these health issues?
  - a. Are some families facing these barriers more than others?
6. Are there health concerns emerging among children with special healthcare needs and their families that are not so pressing currently, but potentially could be?

### **A. PROGRAM / SERVICE ENVIRONMENT (20 minutes)** *[For public health, advocacy, parent advisory group, and school interviewees]*

7. Let's talk about a few of the issues you mentioned previously. [FOR EACH ISSUE]  
What programs, services, policies or initiatives are you aware of that address this issue?
  - a. In your opinion, how effective have these been at addressing this issue? Why?
8. What would you say are some of the strongest assets relative to services and supports for children with special healthcare needs and their families in New Jersey? [PROBE ON: policies, advocacy, coalitions, larger initiatives]
9. What program, services, policies or initiatives are currently not available that you think should be?
  - b. What do you think needs to be done to address these gaps?
  - c. Do you see opportunities currently out there that can be seized upon to address these issues? For example, are there some "low hanging fruit" – current collaborations or initiatives that can be strengthened or expanded?
  - d. Do you see a role for Children's Specialized in addressing these gaps?

**B. PROGRAM / SERVICE ENVIRONMENT (20 minutes)** *[For services provider interviewee(s)]*

I'd like to spend a few minutes talking specifically about what youth with special healthcare needs and their families face as they plan for and transition to adulthood.

I'd like to talk first about needs and available services for youth and their families **as they plan for transition** to adulthood.

**10. What specific concerns or challenges come up as youth and their families plan for transition to adulthood?** [PROBE ON: employment/career and education planning, medical care, housing, social activities]

**11. What services or programs currently exist to address these concerns or challenges? Are these generally available to families that need them? What barriers to access exist?**

**12. What other services or policies do you think are needed to better support youth with special healthcare needs and their families as young people plan for transition to adulthood?**

- a. Do you see "low hanging fruit" opportunities that can be seized upon to address these issues?
- b. Do you see a role for Children's Specialized in addressing these gaps?

I'd like to now talk more specifically about needs and available services for youth **after they transition** to adulthood.

**13. What specific concerns or challenges come up for youth once they transition to adulthood?**

**14. What services or programs currently exist to address these concerns or challenges? Are these generally available to families that need them? What barriers to access exist?**

**15. What other services or policies do you think are needed to better support youth once they transition to adulthood?**

- a. Do you see "low hanging fruit" opportunities that can be seized upon to address these issues?
- b. Do you see a role for Children's Specialized in addressing these gaps?

**CLOSING (2 minutes)**

Thank you so much for your time. That is it for my questions. Is there anything else that you would like to mention that we did not discuss today?

Your feedback is going to help Children's Specialized in their program planning. We greatly appreciate your time and you sharing your opinion. Have a good afternoon/morning.

## Appendix C: Focus Group Guide: Transition-age youth (≥ 18 years) and their parents/caregivers

### Goals of the focus group

- To identify experiences and needs of transition-age youth with special healthcare needs and their parents/caregivers
- To explore the role CSH can play in addressing the needs of transition-age youth with special healthcare needs

### BACKGROUND AND INTRODUCTIONS (10-15 minutes)

- Hello. Thank you for taking the time to speak with us today. My name is XX, and I am joined by my colleague, XX. We are with Health Resources in Action, a nonprofit public health organization.
- We are here to help Children's Specialized Hospital better understand experiences with community and hospital services for children and youth with special healthcare needs, and what is needed. We are having several conversations like this with groups and individuals. The purpose of these conversations is to provide the hospital with information about the community it serves. The hospital will use this information to develop an action plan to better serve the community.
- In this conversation we would like to talk specifically about needs young people and their families have when planning for the transition to adult systems and during and after that transition. We know this is an important issue, and an area where more work needs to be done.
- We are here to learn about your experiences—what's working, what are the barriers, where more services and programs are needed. We want to hear your opinions. There are no right or wrong answers and we appreciate your feedback, insight, and honesty.
- After our data collection, we will write a summary report of the general themes that come up during the discussions. We will not include any names or identifying information in that report. All names and responses will be confidential.
- Our conversation will last about 90 minutes. I have some questions I would like to cover and my role is to make sure everyone who wants to answer those questions is able to.
- Does anyone have any questions before we begin?

**Let's first spend a little time getting to know one another. Let's go around and introduce ourselves. When I call your name, please unmute yourself and tell us: 1) Your first name; 2) the town you live in; and 3) something about yourself you'd like to share—such as your favorite movie or an activity you like to do for fun. I'll start...**

## PREPARING FOR TRANSITION TO ADULT SYSTEMS

1. Let's talk first about current programs and services in the community that support young people with special healthcare needs.

### YOUTH PARTICIPANTS

**What types of programs do you like to participate in?** [PROBE: sports, arts programs, programs that help with homework or school]

- What do you like about these?
- What don't you like about these?

### PARENT/CAREGIVER PARTICIPANTS

**What programs and services do you currently find most helpful for your children?**

- What do you like about these?
- What don't you like about these?

### YOUTH AND PARENT/CAREGIVER PARTICIPANTS

**Now I'd like to hear from everyone about what is missing. What kinds of programs or services do you wish were available to you?**

- What role could Children's Specialized Hospital play in making these programs and services available?

2. As I mentioned earlier, we are particularly interested in hearing about your experiences planning for and managing the transition from youth-serving to adult-oriented programs, services, and systems. I'd like to start by talking about the process of **planning for transition** to adult services and systems. I realize that a lot is involved in this and thinking about this often happens far before children reach transition age. Some of you may be doing this planning now, others may have done it in the past. We want to hear from everyone.

### YOUTH PARTICIPANTS

**Let's start with the young people. What types of organizations and programs in your community are helping you or have helped you prepare to be successful as a young adult?**

- Does/has anyone participate in programs that help you think about what you might want to do after high school, like maybe learning about jobs or preparing for college, or programs that let you try out different jobs or work in the community?
- Does/has anyone participate in programs that help you to be a leader, in your school or community?
- What do you like about these?
- What don't you like about these?

### PARENT/CAREGIVER PARTICIPANTS

I'd like to ask parents about the services and programs that are or have helped you as you think about your children's transition to adulthood.

**What types of things are you thinking about or you have thought about as you help your child prepare for adulthood?** [PROBES: guardianship, employment and education, housing and independent living, healthcare, social and recreational opportunities]

**Are there programs and services that are helping you with these things?**

- What do you like about these programs or service?
- What don't you like about these?

YOUTH AND PARENT/CAREGIVER PARTICIPANTS

Now I'd like to hear from everyone about what is missing.

**What kinds of programs or services do you wish were available to help youth and their families plan for transition to adulthood?**

**Let's talk a little more about your suggestions. You mentioned [name suggestion].**

**What would you want to see with this/what would it look like?** [Same question for most commonly-cited suggestions]

- What role could Children's Specialized Hospital play in making these programs and services available?

## **SERVICES AND PROGRAMS AFTER TRANSITION TO ADULT SYSTEMS**

- 3.** I'd like to now talk about services and programs that are available to youth and families once they are adults.

YOUTH PARTICIPANTS

**Let's start by talking about the things in your community that are helping you in adulthood. What types of organizations and programs help you to be successful?**

- Are there programs or services that have helped you or are helping you with thinking about and plan for a career?
- Are there programs or services that have helped you or are helping you with independent living and self-care?
- Are there recreational or sports programs?
- Are there programs or services that have helped you or are helping you with transportation?
- Are there people you can turn to help you advocate for yourself?
- What do you like about these?
- What don't you like about these?

PARENT/CAREGIVER PARTICIPANTS

**Now, parents. What challenges or issues are you facing as you support your children in adulthood?** [PROBE: employment and education, housing and independent living, transportation, healthcare, social and recreational opportunities]

**What programs do you find most helpful for your children as they navigate adulthood?**

- What do you like about these programs or service?
- What don't you like about these?

## YOUTH AND PARENT/CAREGIVER PARTICIPANTS

Again, I'd like to hear from everyone about what is missing.

**What kinds of programs or services do you wish were available to help youth and their families as they transition to adulthood?**

**Let's talk a little more about your suggestions. You mentioned [name suggestion].**

**What would you want to see with this/what would it look like?** [Same question for most commonly-cited suggestions]

- What role could Children's Specialized Hospital play in making these programs and services available?

## Appendix D: Children's Specialized Hospital Community Survey

### CHILDREN'S SPECIALIZED HOSPITAL 2025 COMMUNITY HEALTH NEEDS ASSESSMENT SURVEY

Primary administration method of survey was online. Text below is not formatted for respondents.

#### TEXT FOR OUTREACH

Health and wellness matter to everyone. That is why Children's Specialized Hospital and RWJBarnabas Health are asking for your feedback and suggestions on topics that children, adolescents, and young adults with special healthcare needs face in your community.

The survey will take about 10 minutes. We will not ask for anyone's name or contact information, all responses are completely confidential. There are no right or wrong answers; it's your opinion that matters!

When you complete the survey, you have the option to enter a **drawing** for a chance to win a **\$100 gift card to Tango**, which can be used at a variety of retailers and restaurants including Applebee's, Walmart, and AMC theaters, among others. **Two winners will be chosen.**

Begin survey **[PN: INSERT HYPERLINK TO SURVEY]**

**Thank you for your participation!**

#### Welcome to the survey!

Thank you for taking the time to complete our survey. Your willingness to complete the survey will help us better understand how to best serve children, adolescents, and young adults with special healthcare needs in your community.

The survey will take about 10 minutes to complete. We will not ask for your name or contact information on the survey; all responses are kept completely confidential.

At the end of the survey, you will have the option to enter for a drawing to win a \$100 gift card to Tango, which can be used at a variety of retailers and restaurants including Applebee's, AMC theaters, and Walmart, among others. Two winners will be chosen.

Let's shape the future of healthcare for your community together.

1. Please indicate the following about where you live.

**Your County:**

**[PN: INSERT NJ COUNTY LIST. INCLUDE “OTHER” WITH TEXT BOX AND “PREFER NOT TO ANSWER”]**

**Your Town or Municipality:**

**[PN: INSERT TEXT BOX. INCLUDE “PREFER NOT TO ANSWER”]**

**Your Zip Code:**

**[PN: INSERT TEXT BOX. INCLUDE “PREFER NOT TO ANSWER”]**

Throughout this survey, we will be asking questions relating to children, adolescents, and young adults with **special healthcare needs** (Examples may include: autism, ADHD, cerebral palsy, seizure disorder, brain injury, spina bifida, diabetes, cystic fibrosis.)

---

2. Are you a **parent or caregiver** of at least one child/youth with special healthcare needs?

- ☐ Yes **[PN: SKIP TO Q3]**  
☐ No

**[PN: ASK 2A IF “NO” ]**

2a. Do you consider yourself someone with special healthcare needs?

- ☐ Yes  
☐ No **[PN: SKIP TO 2C]**

**[PN: ASK 2B IF “YES”]**

2b. What is your age?

- ☐ Under 18 **[PN: END SURVEY]**  
**[PN: TERM WORDING: Thank you for your interest in our survey. However, to complete this survey you must be 18 years or older.]**  
☐ Over 18 **[PN: SKIP TO 4]**

**[PN: ASK 2C IF 2A IS “NO” ]**

2c. How would you best describe your relationship to a child/youth with special healthcare needs?

- ☐ A family member (e.g., sibling, grandparent, aunt/uncle, etc.)  
☐ A non-family member (e.g., friend, neighbor, etc.)  
☐ Work with children/youth who have special healthcare needs (Please specify where:  
**[PN: INSERT TEXT BOX]**)

☐ Other (Please specify: **[PN: INSERT TEXT BOX]**)

**[PN: SKIP TO Q4 FOR ALL ABOVE]**

- ☐ I do not know any children/youth, or work with any children/youth who have special healthcare needs. **[PN: END SURVEY]**

**[PN: TERM WORDING: Thank you for your interest in our survey. However, we are looking for those who know or work with a child /youth with special healthcare needs.]**

**[PN: ASK 3 IF “PARENT/CAREGIVER” IN Q2. ALLOW MULTIPLE RESPONSES.]**

3. What facilities have you ever used for your child(ren) with special healthcare needs? (Select all that apply.)

- ☐ Children’s Specialized Hospital
- ☐ Children’s Hospital of Philadelphia (CHOP)
- ☐ The Wanaque Center for Nursing and Rehabilitation
- ☐ Weisman Children’s Rehabilitation Hospital
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX]** )
- ☐ Don’t know **[PN: SINGLE RESPONSE]**

## BARRIERS TO CARE

4. Please think about the different types of services and programs that are available for children/youth with special healthcare needs and their families.

How easy or hard is it to access each of the following?

	Very Easy	Easy	Not Easy or Hard	Hard	Very Hard	Don’t know
Primary care for children/youth with special healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialty care for children/youth with special healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental care for children/youth with special healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral/mental healthcare for children/youth with special healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreational programs for children/youth with special healthcare needs (e.g., camps, concerts, social events, art programs, sports programs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Educational programs for children/youth with special healthcare needs (e.g., preschool, special education programs, K–12 education, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support groups for <b>children/youth</b> with special healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support groups for <b>parents/caregivers/siblings</b> of children/youth with special healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transition to adult services (e.g., job pathways/connections to adult services, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**[PN: ASK FOR EACH STATEMENT BELOW THAT WAS RATED “HARD OR VERY HARD” IN Q4]**

5. You indicated that it was hard to access **[PN: INSERT ATTRIBUTE]**.

What specific services or programs related to **[PN: INSERT ATTRIBUTE]** do you find hard to access and what in particular makes it so hard?

Specialty care for children/youth with special healthcare needs	<b>[PN: INSERT TEXT BOX]</b>
Behavioral/mental healthcare for children/youth with special healthcare needs	<b>[PN: INSERT TEXT BOX]</b>
Recreational programs for children/youth with special healthcare needs	<b>[PN: INSERT TEXT BOX]</b>
Educational programs for children/youth with special healthcare needs	<b>[PN: INSERT TEXT BOX]</b>
Transition to adult services (e.g., job pathways/connections to adult services, etc.)	<b>[PN: INSERT TEXT BOX]</b>

**[PN: IF “PARENT/CAREGIVER” USE 6A QUESTION WORDING. IF YOUNG ADULT WITH SPECIAL HEALTHCARE NEEDS USE 6B WORDING. ALL OTHERS USE 6C QUESTION WORDING. ALLOW MULTIPLE RESPONSES.]**

6a. Over the last few years, which, if any, of the following issues made it hard for you to access healthcare for your child(ren) with special healthcare needs?

6b. Over the last few years, which, if any, of the following issues made it hard for you to access healthcare?

6c. In your opinion, which, if any, of the following issues do you feel make it harder for children/youth with special healthcare needs to get the healthcare that they need? (Select all that apply.)

- ☐ Transportation barriers
- ☐ Have no regular source of healthcare/do not have a doctor or clinic visit on a regular basis
- ☐ Cost of care (e.g., unable to pay/co-pays are too high)
- ☐ Lack of evening and weekend services
- ☐ Insurance problems (e.g., provider not taking insurance/do not have any insurance)
- ☐ Child(ren)/youth was not eligible for services
- ☐ Language problems (e.g., difficulty communicating with doctor or office staff)
- ☐ Discrimination of doctor or office staff
- ☐ Unfriendliness of doctor or office staff
- ☐ Not knowing what type of services are available
- ☐ Not getting accurate/up-to-date information about services available
- ☐ No available provider (e.g. primary care, mental health specialist, developmental behavioral pediatrician, etc.) near me
- ☐ Lack of communication among child(ren)’s provider(s)/care team(s)/care seems uncoordinated
- ☐ Long wait at appointment time to see doctor
- ☐ Have to wait too long to get an appointment
- ☐ Other (Please specify:) **[PN: INSERT TEXT BOX]**
- ☐ I have never experienced any difficulties getting care for my child(ren) **[PN: SINGLE RESPONSE. ONLY SHOW FOR “PARENT/CAREGIVER”]**
- ☐ Don’t know **[PN: SINGLE RESPONSE]**

**[PN: ASK 7, 8, 9 IF “PARENT/CAREGIVER” IN Q2. SKIP IF YOUNG ADULT WITH SPECIAL HEALTHCARE NEEDS AND ALL OTHERS.]**

7. How often are you unable to get your child with special healthcare needs to where they need to go because of not having a way to get there?

- ☐ Rarely or infrequently      ☐ About once a month      ☐ Once a week or more often  
☐ Several times a year      ☐ More than once a month

**8. Please read the following statements that people have made about their food situation.**

For each one, choose how true the statement was for your household over the last 12 months.

	<b>Often True</b>	<b>Sometimes True</b>	<b>Never True</b>
We worried whether our food would run out before we got money to buy more.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The food that we bought just didn't last and we didn't have money to get more.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We rely on a community supper program, food pantry, or meal assistance program to supplement our household.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Over the past 12 months, have you received food resources from a hospital-based program?

- ☐ Yes  
☐ No  
☐ Not sure

## **ABOUT COMMUNITY**

Now, think about specialty programs and services offered by facilities in your area that serve children with special healthcare needs.

10. Again, think about facilities that serve children/youth with special healthcare needs.

When deciding about future resources, what priority do you feel these facilities should place on each of the following?

	<b>[PN: RANDOMIZE]</b>	Low Priority	Medium Priority	High Priority	Don't know
1.	Increasing the outpatient services (e.g., physical therapy, occupational therapy, speech therapy, support groups, etc.) that are close by and easy to get to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Providing more transportation to and from the facility currently providing health care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Having co-located services (e.g. medical and related services provided in one location)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Increasing the number of certified interpreters at	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	health service provider(s)				
5.	Expanding opportunities for children/youth and their families to participate in research studies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Offering more programs or services that <u>focus on social, emotional and other mental health issues for <b>children/youth with special healthcare needs</b></u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Offering more services or workshops for <b>parents and caregivers</b> of children/youth with special healthcare needs (e.g., support groups, classes, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Offering more services or workshops for <b>siblings</b> of children/youth with special healthcare needs (e.g., support groups, classes, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Providing support to transition to adult services (e.g., job pathways/connections to adult services, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Offering more community-based programs for children/youth with special healthcare needs (i.e., clubs and camps, recreational programs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Providing early developmental screenings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Better coordinating, integrating, and communicating between a child's school and their healthcare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Other resource (Please specify): <b>[PN: INSERT TEXT BOX]</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If 10-6 (social-emotional programs) is selected as “MEDIUM OR HIGH PRIORITY”**

You indicated that priority should be given to offering more programs or services that focus on social, emotional and other mental health issues for children/youth with special healthcare needs.

What priority do you think should be given to each of the following programs and services to address social, emotional and other mental health issues for children/youth with special healthcare needs?

<b>[PN: RANDOMIZE]</b>	Low Priority	Medium Priority	High Priority	Don't know
Mental health evaluations/services from providers other than physicians (Advanced Practice Nurses, Licensed Clinical Social Workers, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health services for transition age youth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services/support for emotional health of parents/caregivers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services/support for emotional health of siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School-based mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify:)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If 10-9 (transition services) is selected as “MEDIUM OR HIGH PRIORITY”**

You indicated that priority should be given to offering more programs or services that focus on supporting children/youth with special healthcare needs with the transition to adulthood.

What priority do you think should be given to each of the following programs and services to support children/youth with special healthcare needs with the transition to adulthood?

<b>[PN: RANDOMIZE]</b>	Low Priority	Medium Priority	High Priority	Don't know
Programs to support parents/caregivers with transition planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guardianship planning services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services/programs to support employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services/programs to support connection to educational opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services/programs to support connection to housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services/programs to support transition from pediatric to adult healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social and recreational programs/activities for transition age youth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify:)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**[PN: ASK FOR EACH STATEMENT BELOW THAT WAS RATED “MEDIUM OR HIGH PRIORITY” IN Q10—THAT ARE NOT TRANSITION SERVICES OR SOCIAL-EMOTIONAL]**

11. You indicated that priority should be given to **[PN: INSERT ATTRIBUTE]** .

What specific services or programs relative to **[PN: INSERT ATTRIBUTE]** would you like to see offered?

Increasing the outpatient services (e.g., physical therapy, occupational therapy, speech therapy, support groups, etc.) that are close by and easy to get to	<b>[PN: INSERT TEXT BOX]</b>
Providing more transportation to and from the facility currently providing health care services	<b>[PN: INSERT TEXT BOX]</b>
Offering more community-based programs for children/youth with special healthcare needs (i.e., clubs and camps, recreational programs)	<b>[PN: INSERT TEXT BOX]</b>
Better coordinating, integrating, and communicating between a child's school and their healthcare providers	<b>[PN: INSERT TEXT BOX]</b>

**THESE QUESTIONS ONLY FOR PARENT/CAREGIVER AND YOUNG ADULT WITH SPECIAL HEALTHCARE NEEDS. DO NOT INCLUDE FOR THOSE WHO WORK WITH CHILDREN WITH SPECIAL HEALTHCARE NEEDS.**

These questions ask about your use of and satisfaction with virtual medical care (telehealth).

12. Have you ever used telehealth (i.e., through Doxy) to access medical care for your child with special healthcare needs?

- ☐ Yes
- ☐ No

## IF YES

12a. Over the past 12 months, how often did you use telehealth to access medical care for your child with special healthcare needs?

- ☐ Once
- ☐ Between 2 and 5 times
- ☐ Between 6 and 10 times
- ☐ More than 10 times

12b. Why do you use telehealth to access medical care for your child with special healthcare needs? (Select all that apply.)

- ☐ It saves time
- ☐ Less disruption for my child
- ☐ My child is able to see providers who are far from our home
- ☐ I don't need to take time off work or arrange for childcare
- ☐ I am able to get an appointment for my child more quickly than an in-person visit
- ☐ Less exposure to illness for my child
- ☐ My child has mobility challenges
- ☐ We do not have reliable transportation to get to in-person appointments
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX]** )

12c. How satisfied are you with telehealth services to access medical care for your child with special healthcare needs?

- ☐ Very satisfied – It was great
- ☐ Satisfied – It was okay
- ☐ Not satisfied – I would only use again if necessary
- ☐ Extremely dissatisfied – Will not use again

## IF NO

12d. What are the main reasons you do not use telehealth to access medical care for your child with special healthcare needs? (Select all that apply.)

- ☐ I prefer in-person medical care for my child
- ☐ I am concerned that providers cannot accurately assess my/my child's needs during a telehealth visit
- ☐ I require/my child requires hands-on support during a medical visit
- ☐ I am concerned about my/my child's ability to communicate/behavior during a telehealth visit
- ☐ We do not have the right technology or internet connection
- ☐ I am not comfortable using technology in this way
- ☐ I am concerned about privacy
- ☐ The provider(s) does not offer telehealth services
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX]** )

## ADDITIONAL COMMENTS

13. Use the space below to expand on a topic previously mentioned or an important health-related topic that was not mentioned in this survey.

[PN: INSERT TEXT BOX]

## DEMOGRAPHICS

**These last few questions are for analysis of this survey and your answers will remain anonymous.**

---

14. What year were you born? \_\_\_\_\_

15. Which most closely describes your gender?

- |  |   |
|--|---|
| <input type="checkbox"/> Woman             | <input type="checkbox"/> Non-binary/gender queer (neither exclusively male or female) |
| <input type="checkbox"/> Man               | <input type="checkbox"/> Agender/I don't identify with any gender                     |
| <input type="checkbox"/> Transgender woman | <input type="checkbox"/> Additional gender category (please specify): _____           |
| <input type="checkbox"/> Transgender man   | <input type="checkbox"/> Prefer not to answer   |

16. What is the highest level of education you have completed?

- |  |  |
|--|--|
| <input type="checkbox"/> Less than high school       | <input type="checkbox"/> Associate or technical degree/certification |
| <input type="checkbox"/> Some high school            | <input type="checkbox"/> College graduate                            |
| <input type="checkbox"/> High school graduate or GED | <input type="checkbox"/> Post-graduate or professional degree        |
| <input type="checkbox"/> Some college                | <input type="checkbox"/> Prefer not to answer                        |

17. How would you describe your ethnic or racial background? (*Check all that apply*).

- ☐ Black or African American (e.g., African American, Haitian, Jamaican, Nigerian, Ethiopian)
- ☐ Latino/a or Hispanic of Caribbean descent (e.g., Puerto Rican, Cuban, Dominican)
- ☐ Latino/a or Hispanic of Mexican or Central or South American descent (e.g., Mexican, Salvadorian, Brazilian, Columbian)
- ☐ East Asian (e.g., Chinese, Japanese, Korean, Filipino, Vietnamese)
- ☐ South Asian (e.g., Indian, Pakistani, Bangladeshi, Nepalese)
- ☐ Middle Eastern/North African/Arab (e.g., Egyptian, Moroccan, Jordanian, Syrian)
- ☐ White/European American (e.g., German, Irish, English, Italian, Polish)
- ☐ American Indian/Native American (e.g., Nanticoke Lenni-Lenape, Powhatan Renape, Ramapough)
- ☐ Native Hawaiian or Other Pacific Islander (e.g., Hawaiian, Samoan)
- ☐ Other (please specify): \_\_\_\_\_
- ☐ Prefer not to answer

**[PN: ASK Q18 IF “PARENT/CAREGIVER”. ALLOW MULTIPLE RESPONSES]**

18. At this time, is(are) your child(ren) covered by health insurance, including private health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

- ☐ Yes, private health insurance (through employer/spouse’s employer or bought on own)
- ☐ Yes, government plan (Medicaid/State Children’s Health Insurance Program or other)
- ☐ No health insurance **[PN: SINGLE RESPONSE]**
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX]**)
- ☐ Don’t know **[PN: SINGLE RESPONSE]**

---

**[PN: ASK Q19 IF Q2A “Work with children/youth that have special healthcare needs.” SINGLE RESPONSE.]**

19. What type of organization do you work for?

- ☐ Advocacy organization
- ☐ Faith-based organization
- ☐ Government agency
- ☐ Healthcare organization
- ☐ School
- ☐ Social services organization
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX]**)
- ☐ Prefer not to answer

**PN: ASK Q20 IF Q2A “Work with children/youth that have special healthcare needs.” SINGLE RESPONSE.]**

20. What position do you hold at your organization?

- ☐ Physician
- ☐ Nurse
- ☐ Social worker
- ☐ Other type of clinician
- ☐ Executive Director/Senior Staff
- ☐ Project Director
- ☐ Program Manager/Coordinator
- ☐ Teacher
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX]**)
- ☐ Prefer not to answer

---

**[PN: ASK Q21, Q22, Q23 IF “PARENT/CAREGIVER”. ALLOW MULTIPLE RESPONSES]**

21. Please indicate the age of your child(ren) with special healthcare needs.

- ☐ Younger than 5 years of age
- ☐ 5–9 years of age
- ☐ 10–14 years of age
- ☐ 15–18 years of age
- ☐ 19–21 years of age
- ☐ Older than 21 years of age

22. What is the primary language you speak at home?

- ☐ English
- ☐ Spanish
- ☐ Haitian/Creole
- ☐ Arabic
- ☐ Chinese
- ☐ Hindi
- ☐ Portuguese
- ☐ Other (please specify): **[PN: INSERT TEXT BOX]**
- ☐ Prefer not to answer

23. Which most closely describes your annual household income before taxes? *Household income is the total money earned by everyone living in your home in the past year (e.g., income earned, alimony received, etc.).*

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Less than \$10,000   | <input type="checkbox"/> \$35,000 to \$49,999   | <input type="checkbox"/> \$150,000 to \$199,999 |
| <input type="checkbox"/> \$10,000 to \$14,999 | <input type="checkbox"/> \$50,000 to \$74,999   | <input type="checkbox"/> \$200,000 or more      |
| <input type="checkbox"/> \$15,000 to \$24,999 | <input type="checkbox"/> \$75,000 to \$99,999   | <input type="checkbox"/> Prefer not to answer   |
| <input type="checkbox"/> \$25,000 to \$34,999 | <input type="checkbox"/> \$100,000 to \$149,999 |   |

---

24. Would you like to enter the **drawing** for a chance to win a **\$100 gift card to Tango**?

There will be **two winners chosen**.

- ☐ Yes **[PN: SEND TO NEW LINK TO GATHER INFORMATION]**
- ☐ No **[PN: THANK AND END SURVEY]**

***Thank you very much for your time and cooperation.***

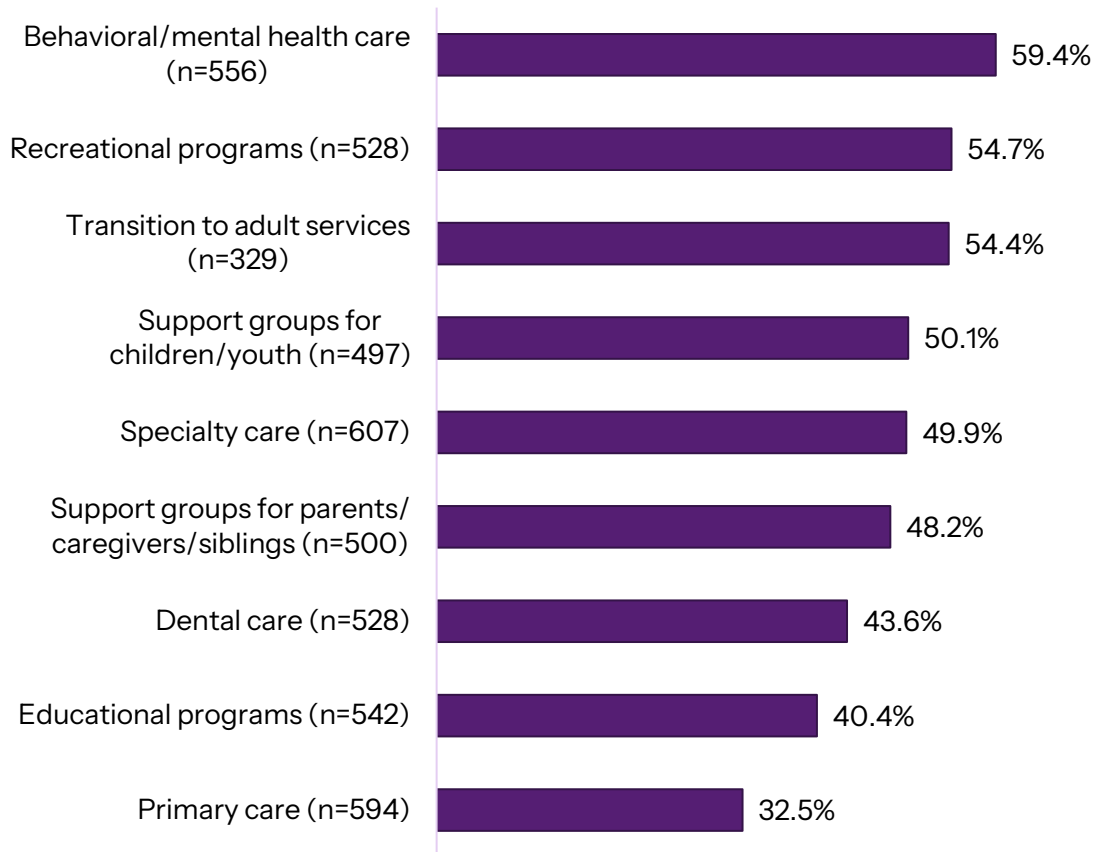
## Appendix E: Children’s Specialized Hospital Community Survey Results

**Table 20. Characteristics of CSH Community Health Needs Assessment Survey Respondents (N=637)**

	n		
All Respondents	637		
Parents/Caregivers	578		
Other Respondents	59		
All Respondent Characteristics			
Race/Ethnicity (n=385)		Gender Identity (n=415)	
Black/African American, Non-Hispanic	15.3%	Woman	87.0%
Asian, Non-Hispanic	6.2%	Man	9.2%
White, Non-Hispanic	45.7%	Transgender Man	0.2%
Hispanic/Latino(a)	28.6%	Agender/I don't identify with any gender	0.2%
Other/Multiracial, Non-Hispanic	4.2%	Other gender category	0.5%
		Prefer not to answer	2.9%
Age (n=402)		Education (n=420)	
18-21 years	0.2%	Less than high school	0.5%
22-24 years	1.2%	Some high school	1.0%
25-34 years	12.4%	High school graduate or GED	15.2%
35-44 years	37.8%	Some college	14.0%
45-54 years	32.6%	Associate or technical degree/certification	12.9%
55-64 years	11.7%	College graduate	26.0%
65-74 years	2.5%	Post-graduate or professional degree	28.3%
75+ years	1.5%	Prefer not to answer	2.1%
Parent/Caregiver Characteristics			
Race/Ethnicity (n=351)		Age of Child(ren) (n=377)	
Black/African American, Non-Hispanic	16.5%	Under 5 years	11.9%
Asian, Non-Hispanic	6.6%	5-9 years	30.5%
White, Non-Hispanic	43.0%	10-14 years	19.6%
Hispanic/Latino(a)	29.3%	15-18 years	10.9%
Other/Multiracial, Non-Hispanic	4.6%	Over 18 years	10.9%
		Multiple Ages	16.2%
Child's Insurance Status (n=339)		Primary Language Spoken at Home (n=414)	
Public Insurance	48.7%	English	80.9%
Private Insurance	51.3%	Spanish	12.3%
		Haitian/Creole	0.5%
Income (n=309)		Arabic	0.7%
Under \$25,000	18.4%	Chinese	0.2%

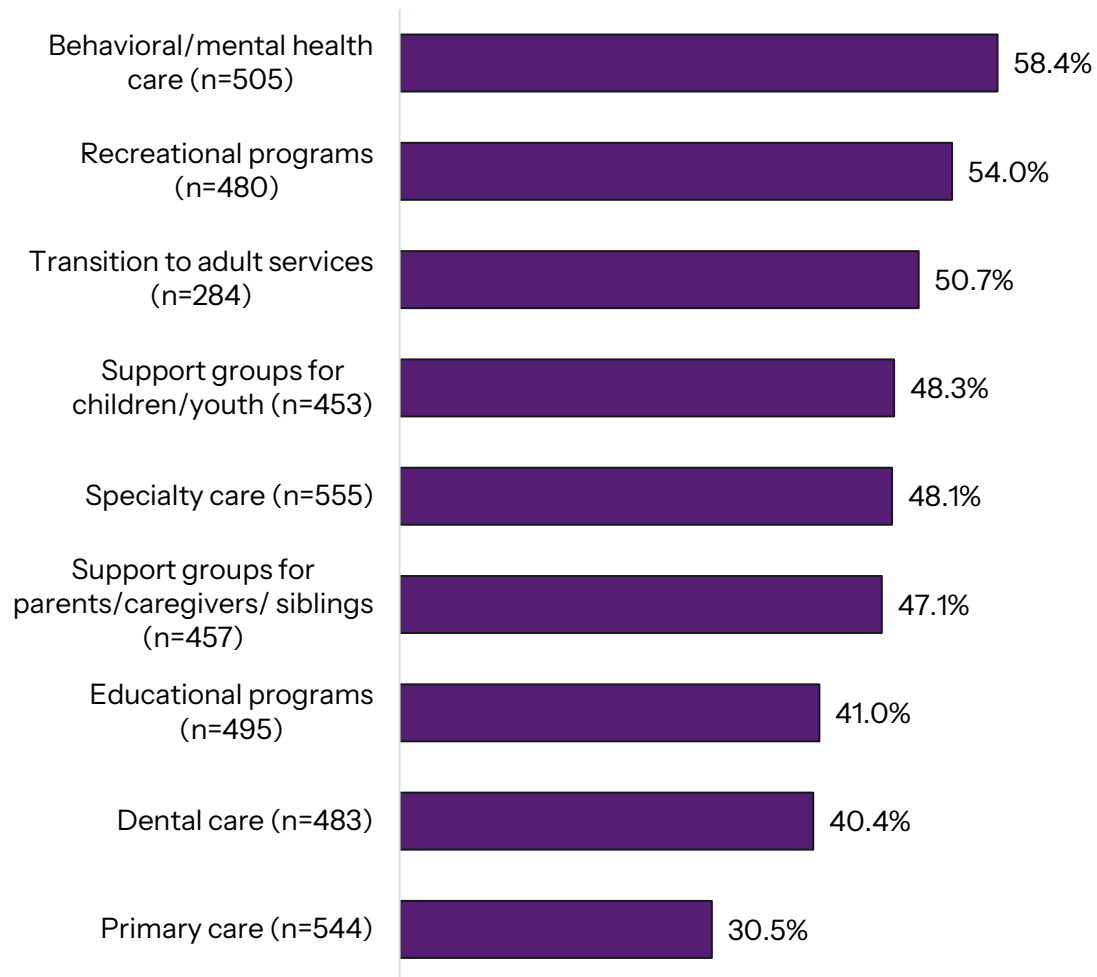
\$25,000 to \$49,999	22.0%	Hindi	0.5%
\$50,001 to \$74,999	11.7%	Portuguese	1.4%
\$75,001 to \$149,999	28.2%	Other	2.9%
Over \$150,000	19.7%	Prefer not to answer	0.5%

**Figure 44. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Healthcare Needs, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 45. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Healthcare Needs, among Parents/Caregivers, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Table 21. Percent of Community Survey Respondents Reporting Issues That Make It Difficult to Access Healthcare for Their Children with Special Healthcare Needs, among Parents/Caregivers, by Race/Ethnicity, 2025**

	<b>Black, non-Hispanic (n=57)</b>	<b>Asian, non-Hispanic (n=22)</b>	<b>White, non-Hispanic (n=149)</b>	<b>Hispanic/Latino (n=102)</b>	<b>Other/2+ Races, non-Hispanic (n=14)</b>
<b>1</b>	Lack of evening and weekend services (40.4%)	Lack of evening and weekend services (50.0%)	Have to wait too long to get an appointment (62.4%)	Have to wait too long to get an appointment (56.9%)	No available provider near me (57.1%)
<b>2</b>	Have to wait too long to get an appointment (36.8%)	Have to wait too long to get an appointment (50.0%)	Lack of evening and weekend services (47.0%)	Lack of evening and weekend services (37.3%)	Lack of evening and weekend services (50.0%)
<b>3</b>	No available provider near me (33.3%)	Insurance problems (45.5%)	Not knowing what type of services are available (44.3%)	Not knowing what type of services are available (31.4%)	Have to wait too long to get an appointment (35.7%)
<b>4</b>	Insurance problems (31.6%)	Long wait at appointment time to see doctor (45.5%)	Insurance problems (43.6%)	No available provider near me (31.4%)	Not knowing what type of services are available (35.7%)
<b>5</b>	Not knowing what type of services are available (31.6%)	Not knowing what type of services are available (40.9%)	No available provider near me (43.0%)	Not getting accurate/up-to-date information about services available (29.4%)	Insurance problems (35.7%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Table 22. Percent of Community Survey Respondents Reporting Issues that Make it Difficult to Access Healthcare for their Children with Special Healthcare Needs, among Parents/Caregivers, by Insurance Status, 2025**

	<b>Private Insurance (n=171)</b>	<b>Government Insurance (n=161)</b>
<b>1</b>	Have to wait too long to get an appointment (62.6%)	Have to wait too long to get an appointment (45.3%)
<b>2</b>	Lack of evening and weekend services (50.9%)	Lack of evening and weekend services (34.8%)
<b>3</b>	No available provider near me (42.1%)	Insurance problems (32.9%)
<b>4</b>	Not knowing what type of services are available (40.4%)	Not knowing what type of services are available (31.7%)
<b>5</b>	Insurance problems (38.0%)	No available provider near me (31.1%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

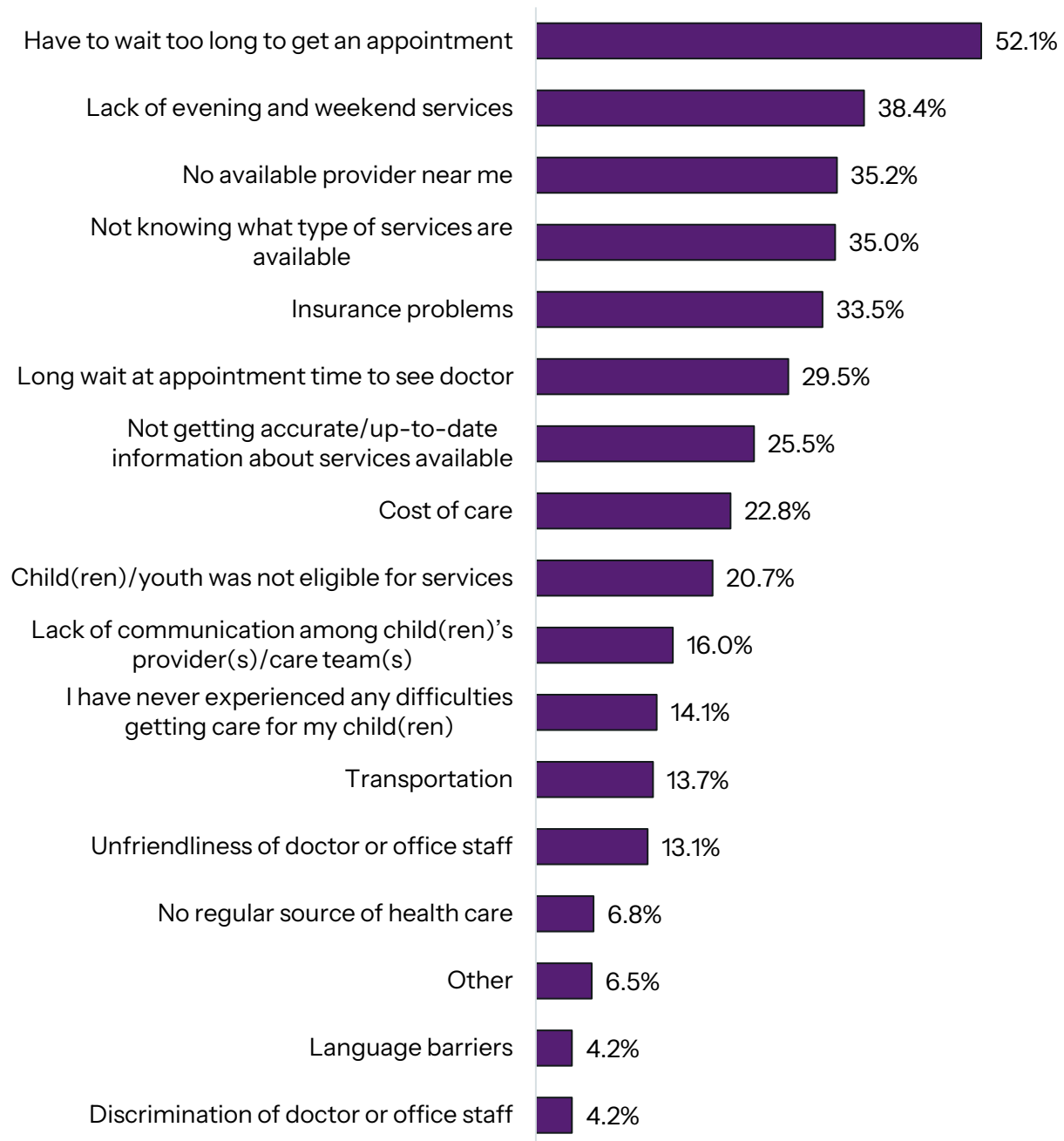
**Table 23. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Healthcare Needs, among Parents/Caregivers, by Age of Child, 2025**

	<b>Under 5</b>	<b>5-9 years</b>	<b>10-14 years</b>	<b>15-18 years</b>	<b>19+ years</b>
<b>1</b>	Behavioral/mental healthcare (53.1%)	Behavioral/mental healthcare (59.0%)	Behavioral/mental healthcare (52.9%)	Transition to adult services (70.8%)	Transition to adult services (65.7%)
<b>2</b>	Recreational programs (45.7%)	Recreational programs (56.1%)	Support groups for children/youth (50.9%)	Specialty care (63.2%)	Behavioral/mental healthcare (63.9%)
<b>3</b>	Specialty care (38.6%)	Specialty care (48.7%)	Recreational programs (50.8%)	Recreational programs (62.9%)	Dental care (58.8%)
<b>4</b>	Dental care (33.3%)	Support groups for parents/caregivers/siblings (46.0%)	Support groups for parents/caregivers/siblings (49.2%)	Behavioral/mental healthcare (61.1%)	Support groups for parents/caregivers/siblings (58.6%)
<b>5</b>	Support groups for children/youth (32.4%)	Educational programs (45.2%)	Transition to adult services (46.0%)	Support groups for children/youth (60.0%)	Support groups for children/youth (58.1%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

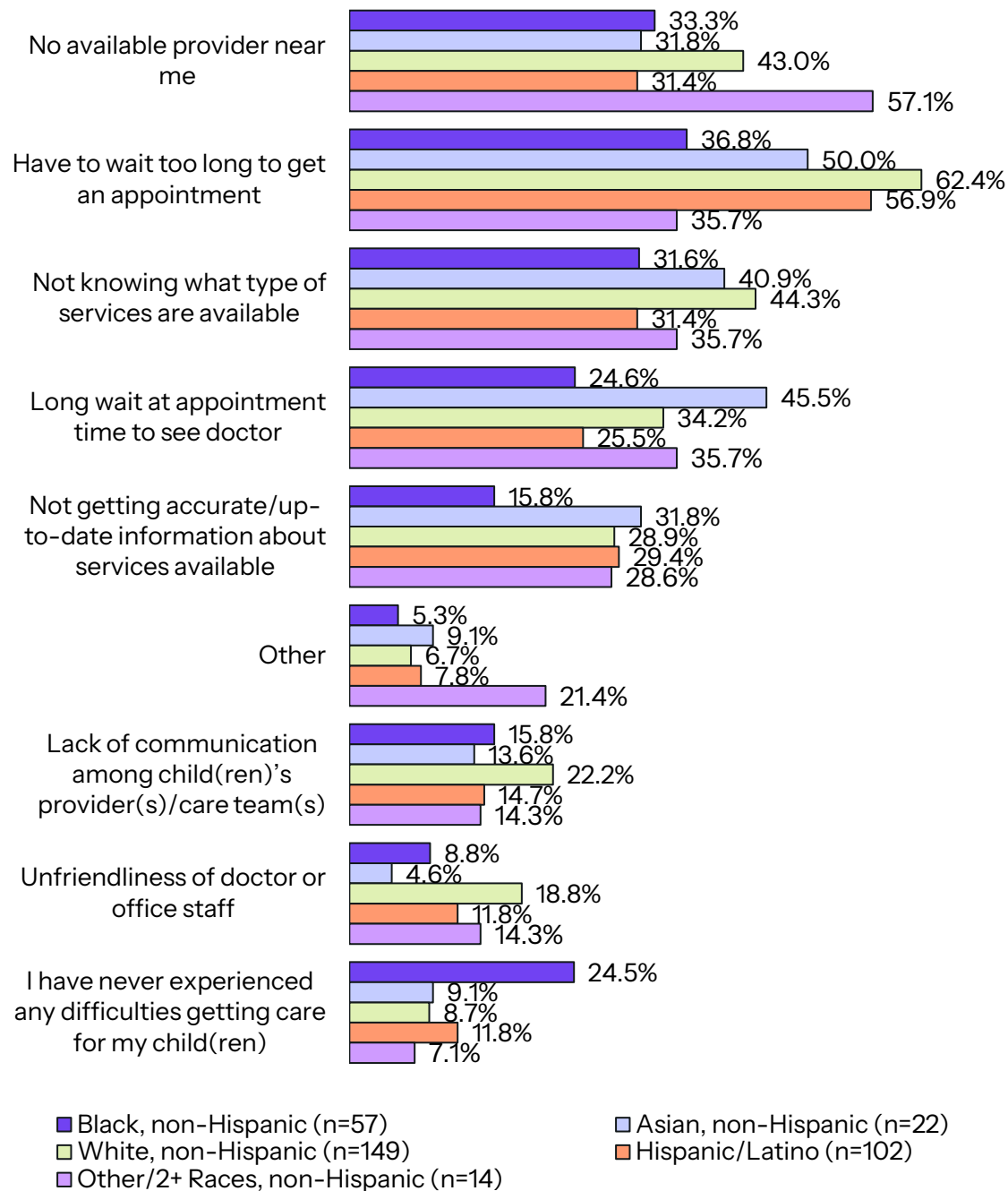
NOTE: The number of respondents in the Under 5 category ranged from n=17 to n=44. The number of respondents in the 5-9 years category ranged from n=38 to n=111. The number of respondents in the 10-14 years category ranged from n=37 to n=73. The number of respondents in the 15-18 years category ranged from n=24 to n=38. The number of respondents in the 19+ category ranged from n=29 to n=39.

**Figure 46. Percent of Community Survey Respondents Reporting Issues that Make it Difficult to Access Healthcare for Children with Special Healthcare Needs, among Parents/Caregivers, 2025**



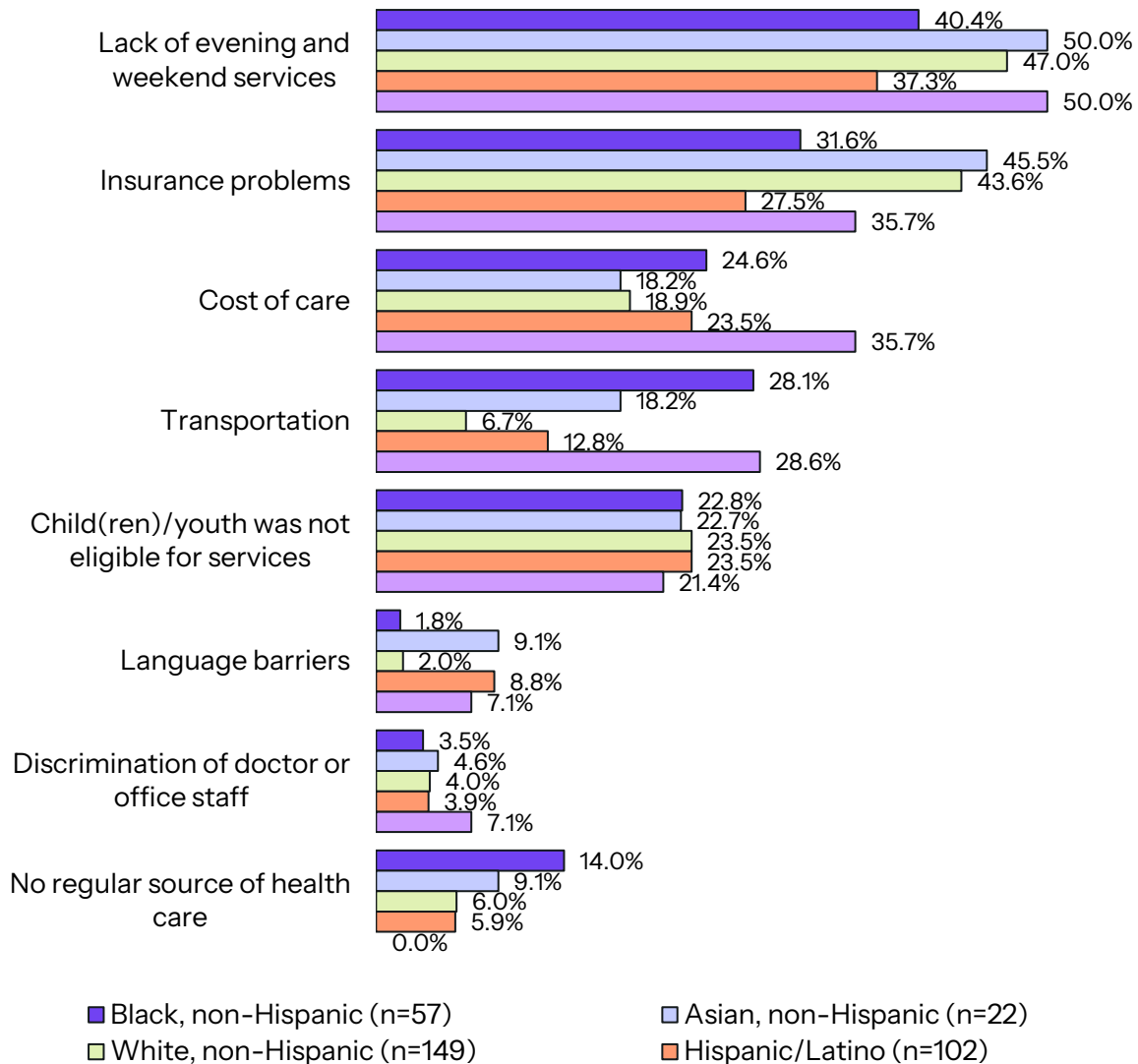
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 47. Percent of Community Survey Respondents Reporting Issues that Make it Difficult to Access Healthcare for Children with Special Healthcare Needs, among Parents/Caregivers by Race/Ethnicity, 2025**



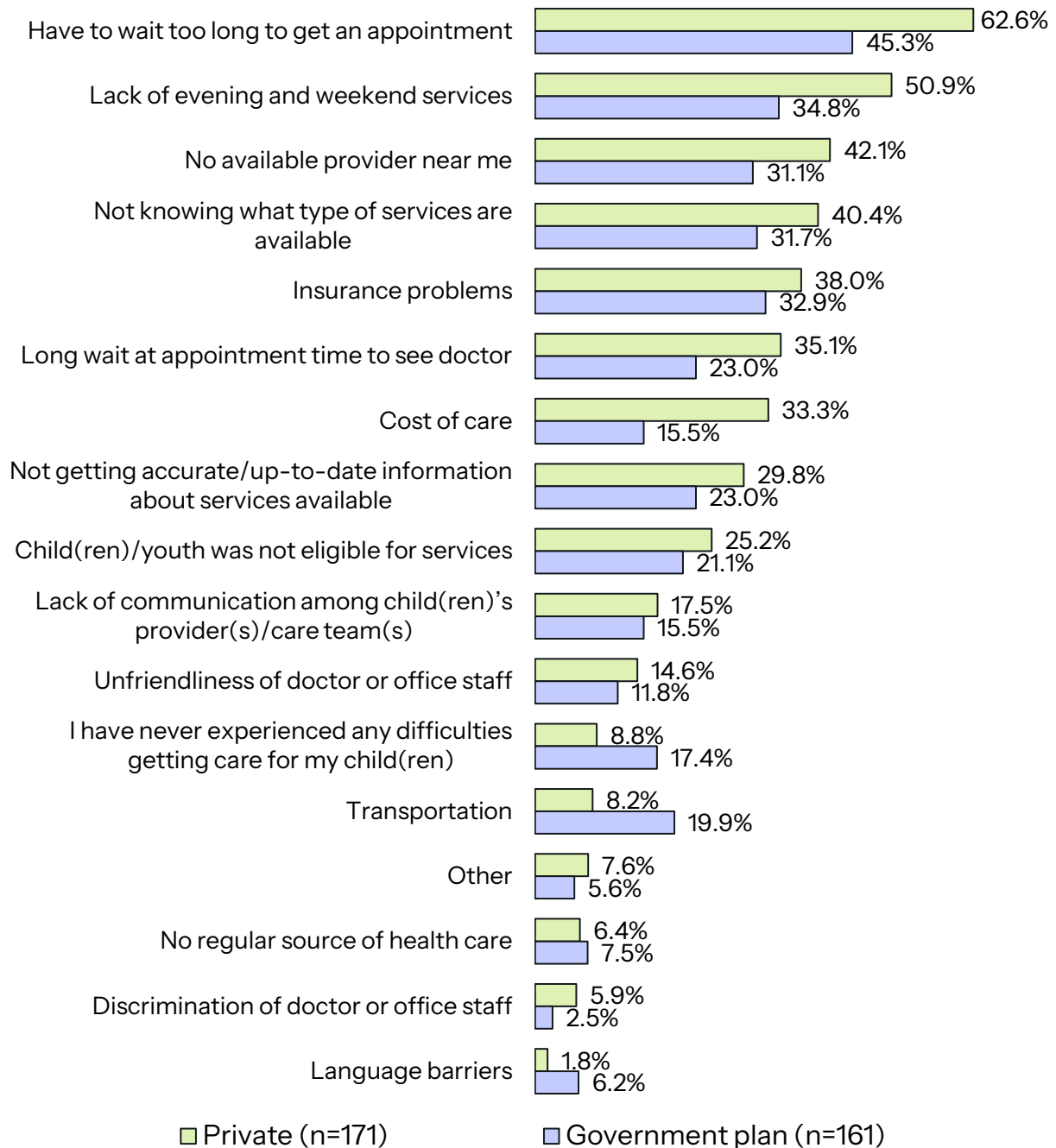
DATA SOURCE: CSH Community Health Needs Assessment Survey, 2025

**Figure 48. Percent of Community Survey Respondents Reporting Issues that Make it Difficult to Access Healthcare for Children with Special Healthcare Needs, among Parents/Caregivers by Race/Ethnicity, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

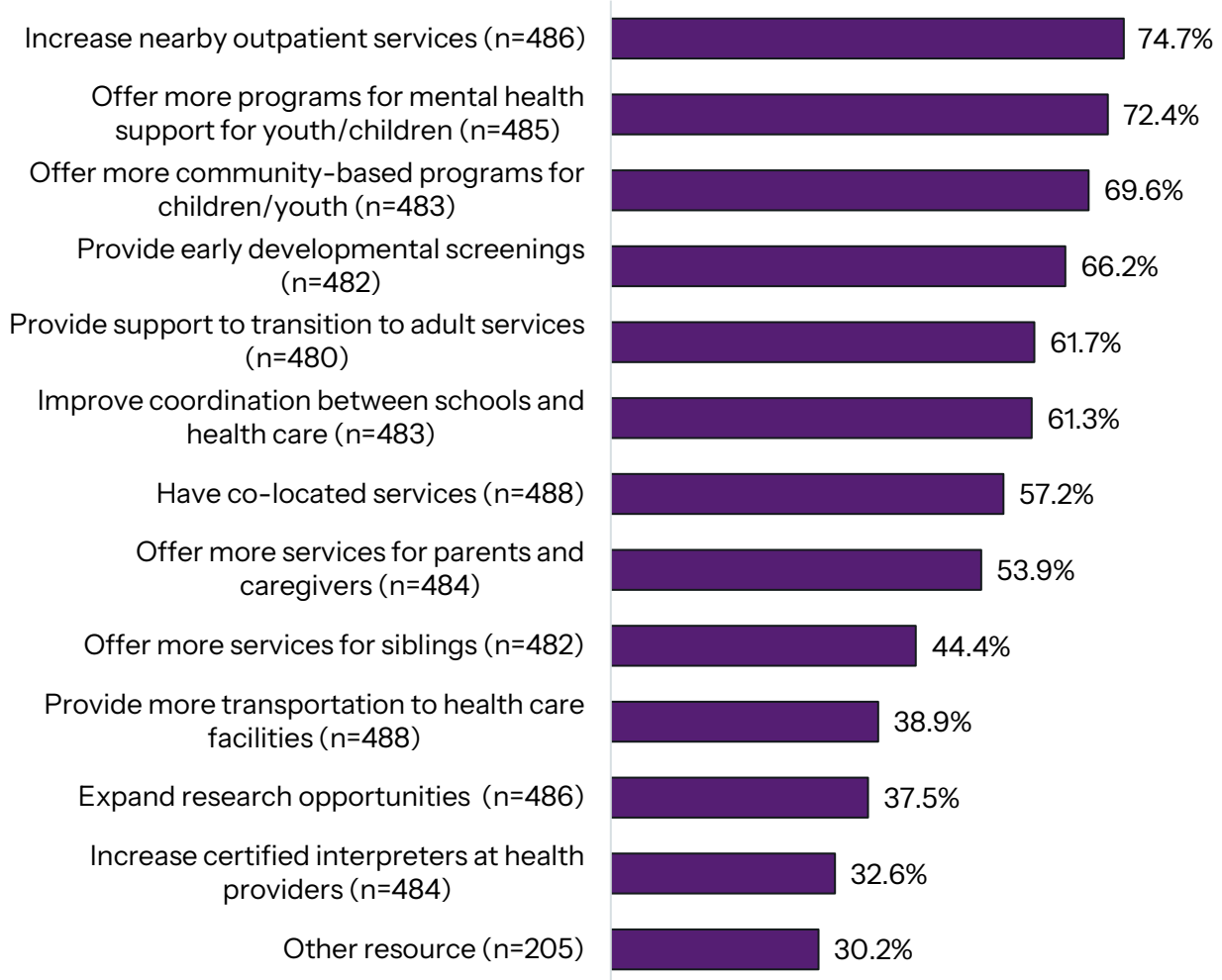
**Figure 49. Percent of Community Survey Respondents Reporting Issues that Make it Difficult to Access Healthcare for Children with Special Healthcare Needs, among Parents/Caregivers, by Insurance Status, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

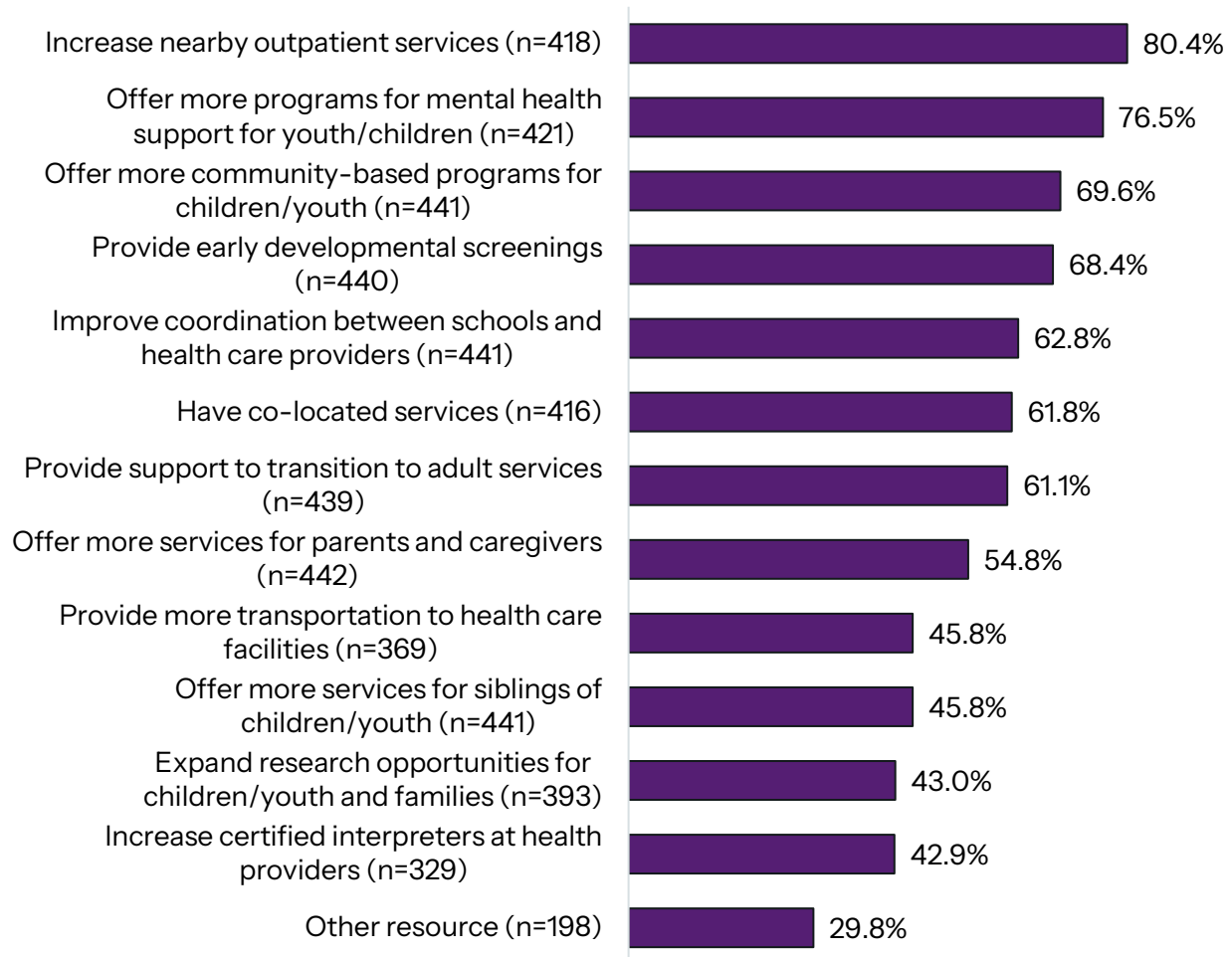
NOTE: The number of respondents in the Private category ranged from n=81 to n=170. The number of respondents in the Government plan category ranged from n=81 to n=159.

**Figure 50. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 51. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Table 24. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Race/Ethnicity, 2025**

	<b>Black, non-Hispanic</b>	<b>Asian, non-Hispanic</b>	<b>White, non-Hispanic</b>	<b>Hispanic/Latino</b>	<b>Other/2+ Races, non-Hispanic</b>
<b>1</b>	Offer more community-based programs for children/youth with special healthcare needs (74.1%)	Increase nearby outpatient services (90.0%)	Offer more programs for mental health support for youth/children with special healthcare needs (75.5%)	Offer more programs for mental health support for youth/children with special healthcare needs (76.8%)	Improve coordination between schools and healthcare providers (87.5%)
<b>2</b>	Offer more programs for mental health support for youth/children with special healthcare needs (70.4%)	Have co-located services (90.0%)	Offer more community-based programs for children/youth with special healthcare needs (68.2%)	Provide early developmental screenings (73.8%)	Offer more community-based programs for children/youth with special healthcare needs (81.3%)
<b>3</b>	Provide more transportation to healthcare facilities (69.4%)	Offer more community-based programs for children/youth with special healthcare needs (86.4%)	Provide early developmental screenings (64.0%)	Offer more community-based programs for children/youth with special healthcare needs (67.7%)	Provide early developmental screenings (80.0%)
<b>4</b>	Provide early developmental screenings (69.4%)	Offer more programs for mental health support for youth/children with special healthcare needs (85.0%)	Provide support to transition to adult services (63.6%)	Improve coordination between schools and healthcare providers (67.7%)	Offer more programs for mental health support for youth/children with special healthcare needs (75.0%)
<b>5</b>	Improve coordination between schools and healthcare providers (65.5%)	Provide early developmental screenings (77.3%)	Provide more transportation to healthcare facilities (61.0%)	Increase certified interpreters at health providers (61.7%)	Provide support to transition to adult services (73.3%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the Black, non-Hispanic category ranged from n=33 to n=58.

The number of respondents in the Asian, non-Hispanic category was n=22. The number of respondents in the White, non-Hispanic category ranged from n=150 to n=151. The number of respondents in the Hispanic/Latino category ranged from n=98 to n=100. The number of respondents in the Other/2+ Races, non-Hispanic category ranged from n=15 to n=16.

**Table 25. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Insurance Status, 2025**

	<b>Private Insurance</b>	<b>Government Plan</b>
<b>1</b>	Increase nearby outpatient services (83.1%)	Offer more programs for mental health support for youth/children with special healthcare needs (82.6%)
<b>2</b>	Offer more programs for mental health support for youth/children with special healthcare needs (72.0%)	Increase nearby outpatient services (80.7%)
<b>3</b>	Offer more community-based programs for children/youth with special healthcare needs (69.4%)	Offer more community-based programs for children/youth with special healthcare needs (70.6%)
<b>4</b>	Provide early developmental screenings (68.2%)	Provide early developmental screenings (69.2%)
<b>5</b>	Improve coordination between schools and healthcare providers (62.4%)	Have co-located services (67.1%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

NOTE: The number of respondents in the private health insurance category ranged from n=120 to n=173. The number of respondents in the government plan category ranged from n=122 to n=160.

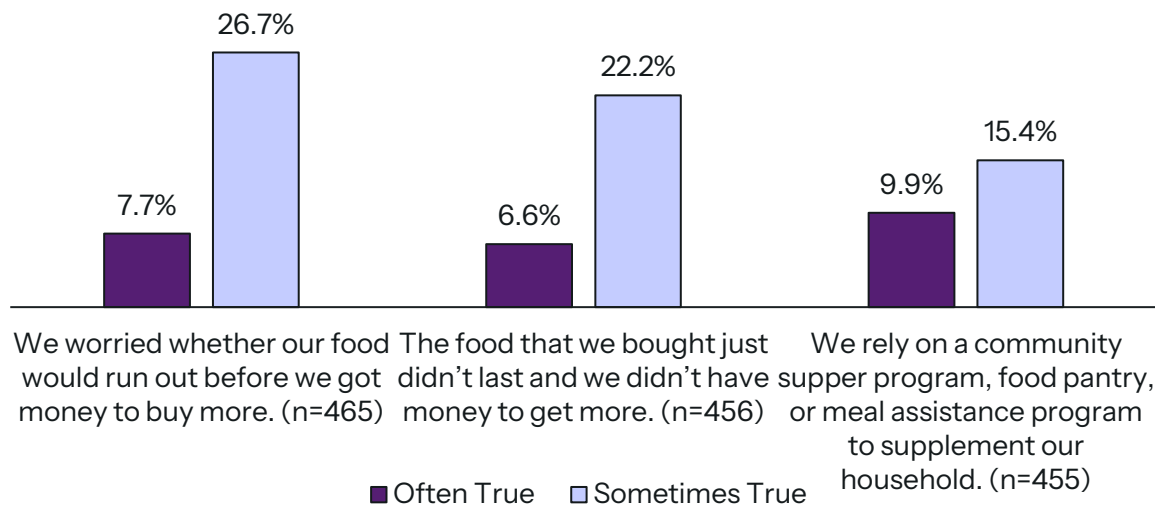
**Table 26. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Age of Child, 2025**

	Under 5	5-9 years	10-14 years	15-18 years	19+
<b>1</b>	Increase nearby outpatient services (88.1%)	Increase nearby outpatient services (85.6%)	Increase nearby outpatient services (72.9%)	Offer more community-based programs for children/youth with special healthcare needs (80.0%)	Provide support to transition to adult services (80.5%)
<b>2</b>	Offer more programs for mental health support for youth/children with special healthcare needs (76.9%)	Offer more community-based programs for children/youth with special healthcare needs (79.5%)	Offer more programs for mental health support for youth/children with special healthcare needs (68.6%)	Offer more programs for mental health support for youth/children with special healthcare needs (79.0%)	Offer more programs for mental health support for youth/children with special healthcare needs (72.5%)
<b>3</b>	Have co-located services (65.9%)	Provide early developmental screenings (79.3%)	Offer more community-based programs for children/youth with special healthcare needs (68.5%)	Increase nearby outpatient services (79.0%)	Increase nearby outpatient services (66.7%)
<b>4</b>	Provide early developmental screenings (62.2%)	Offer more programs for mental health support for youth/children with special healthcare needs (75.2%)	Provide early developmental screenings (57.5%)	Provide support to transition to adult services (72.5%)	Have co-located services (65.8%)
<b>5</b>	Increase certified interpreters at health providers (63.3%)	Improve coordination between schools and healthcare providers (74.1%)	Provide support to transition to adult services (54.2%)	Improve coordination between schools and healthcare providers (65.0%)	Offer more community-based programs for children/youth with special healthcare needs (63.4%)

DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

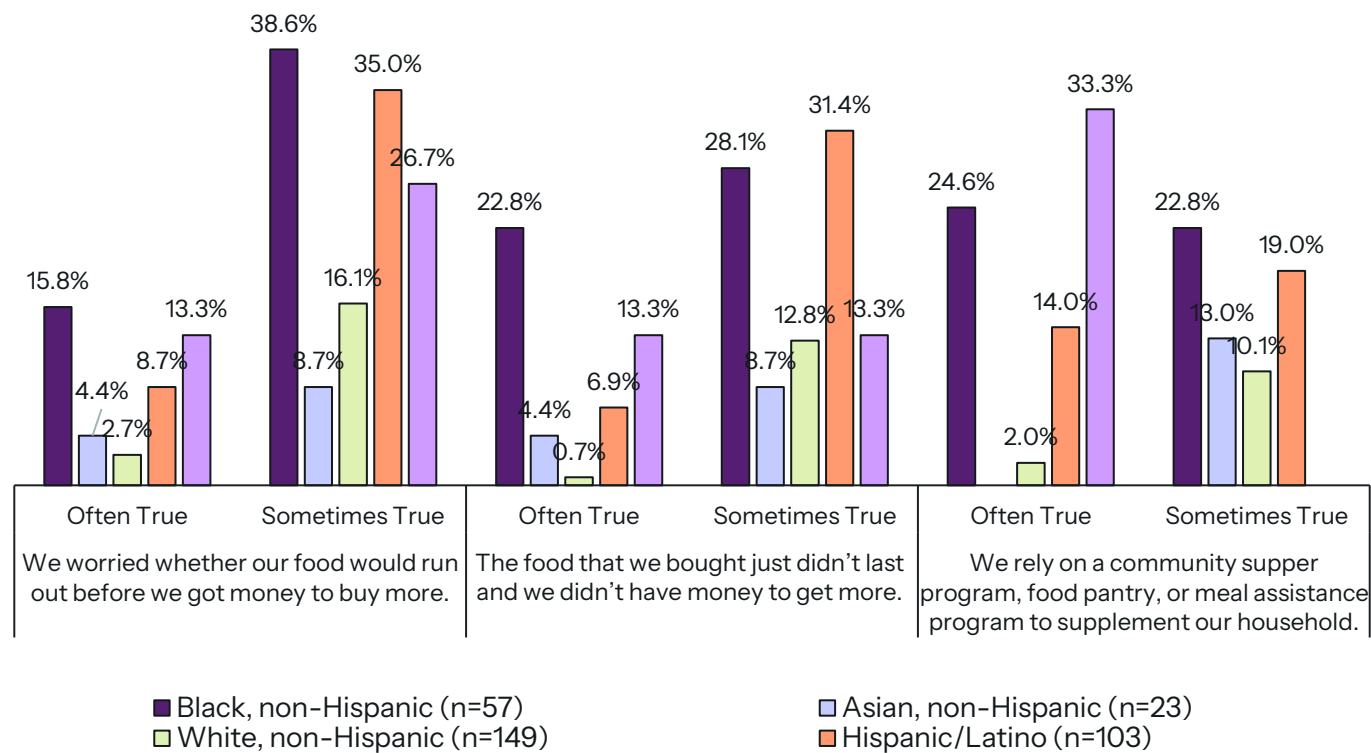
NOTE: The number of respondents in the Under 5 category ranged from n=32 to n=42. The number of respondents in the 5-9 years category ranged from n=84 to n=112. The number of respondents in the 10-14 years category ranged from n=73 to n=151. The number of respondents in the 15-18 years category ranged from n=29 to n=40. The number of respondents in the 19+category ranged from n=29 to n=41. The number of respondents in the multiple ages category ranged from n=49 to n=61.

**Figure 52. Percent of Community Survey Respondents Reporting Difficulty with Food Access, among Parents/Caregivers, 2025**



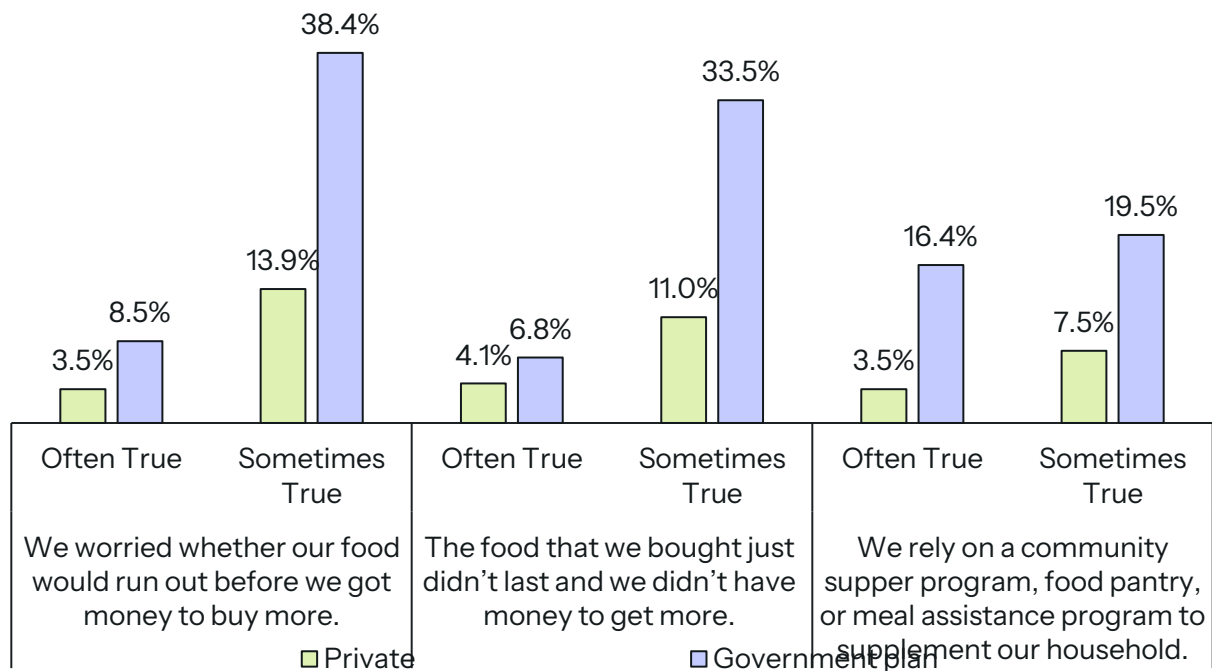
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 53. Percent of Community Survey Respondents Reporting Difficulty with Food Access, among Parents/Caregivers, by Race/Ethnicity, 2025**



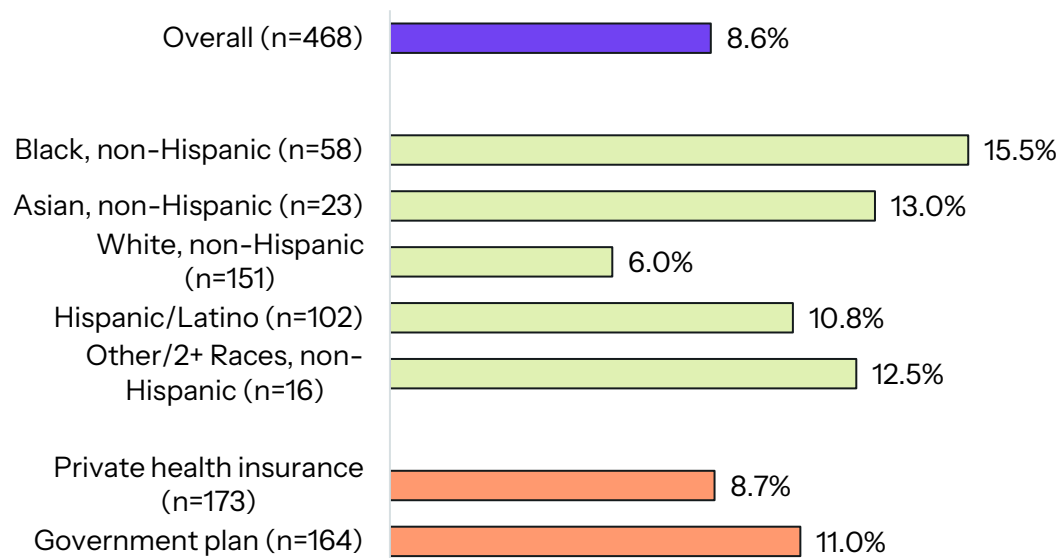
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 54. Percent of Community Survey Respondents Reporting Difficulty with Food Access, among Parents/Caregivers, by Insurance Status, 2025**



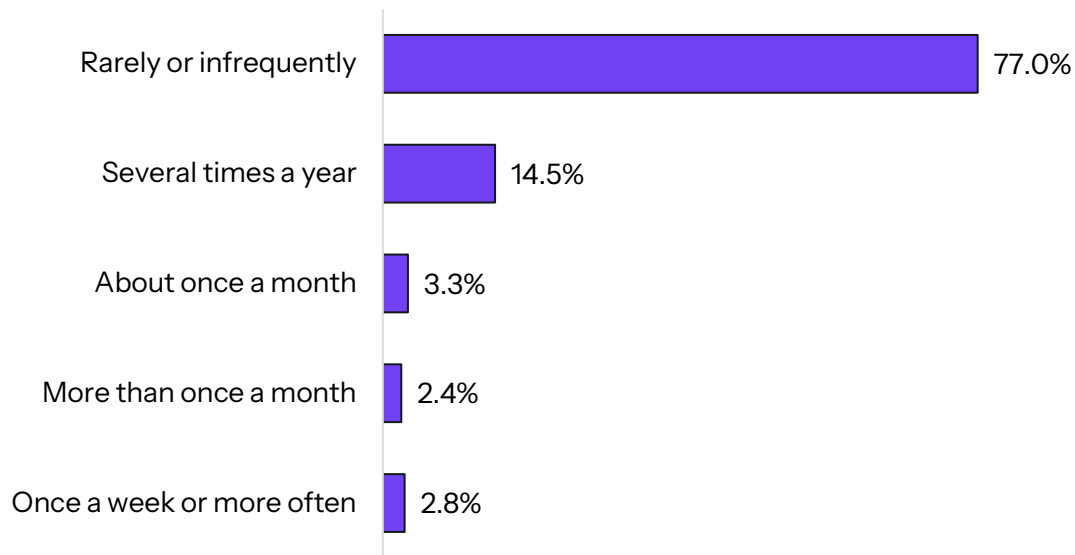
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 55. Percent of Community Survey Respondents Reporting Receiving Food Resources from a Hospital-Based Program, among Parents/Caregivers, 2025**



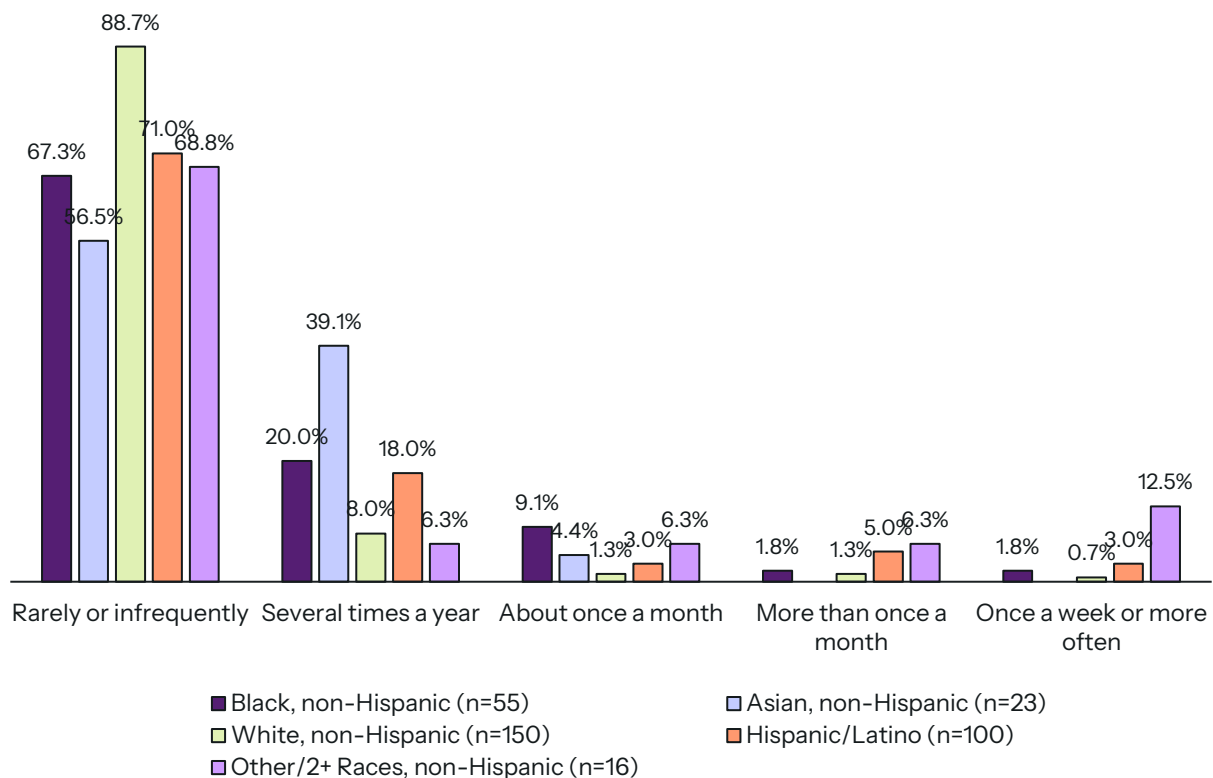
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 56. Percent of Community Survey Respondents Reporting Frequency of Transportation Barriers, among Parents/Caregivers, 2025**



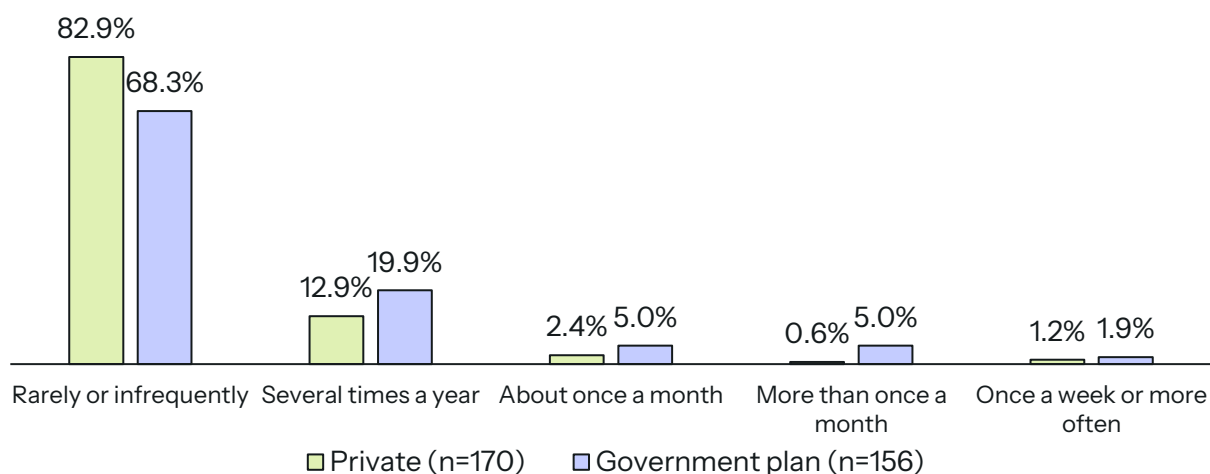
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 57. Percent of Community Survey Respondents Reporting Frequency of Transportation Barriers, among Parents/Caregivers, by Race/Ethnicity, 2025**



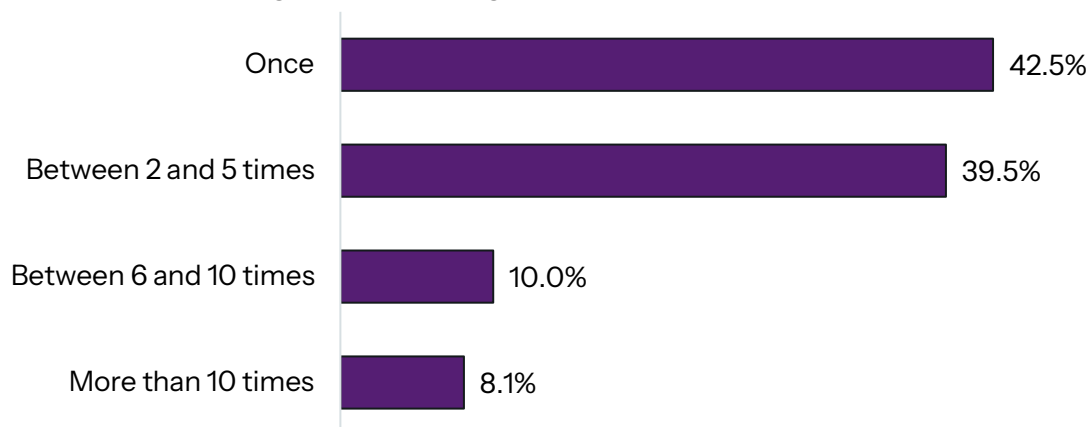
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 58. Percent of Community Survey Respondents Reporting Frequency of Transportation Barriers, among Parents/Caregivers, by Insurance Status, 2025**



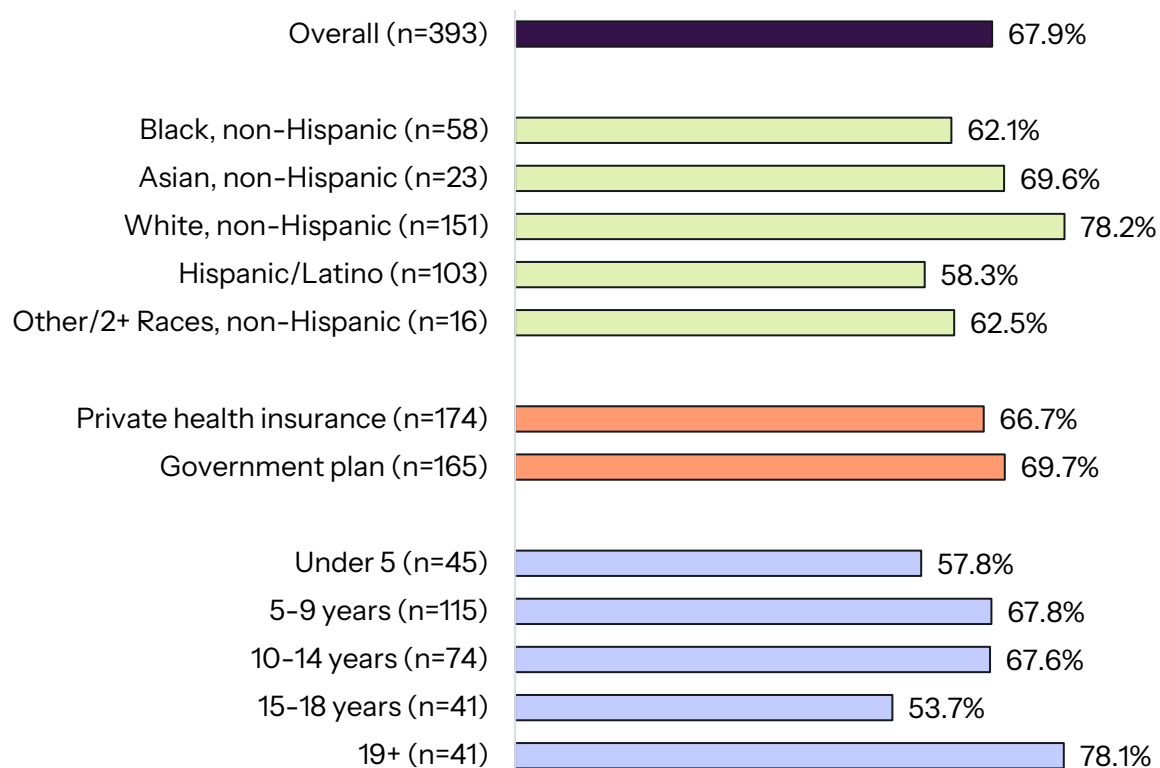
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 59. Percent of Community Survey Respondents Reporting Frequency of Telehealth Use, among Parents/Caregivers, 2025 (n=261)**



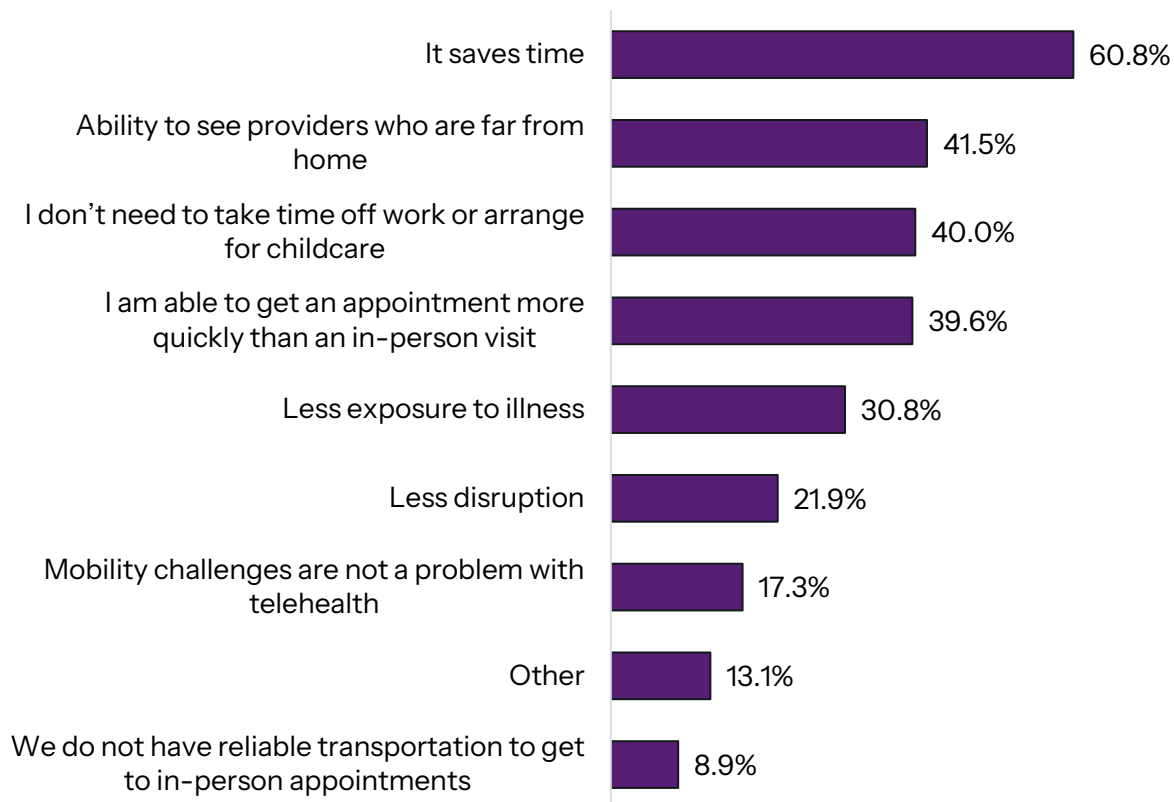
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 60. Percent of Community Survey Respondents Indicating That They Have Used Telehealth, among Parents/Caregivers, 2025**



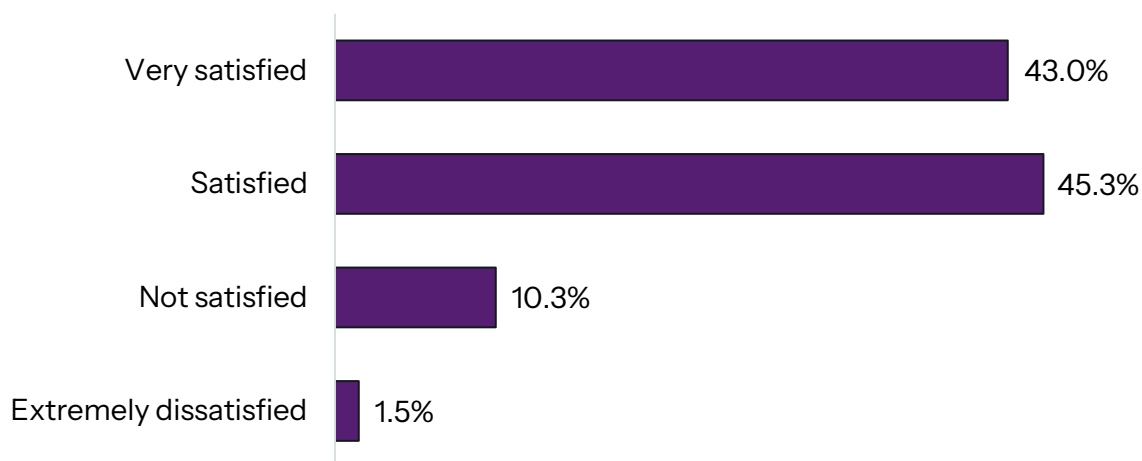
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 61. Reasons for Telehealth Use, among Parents/Caregivers, 2025 (n=260)**



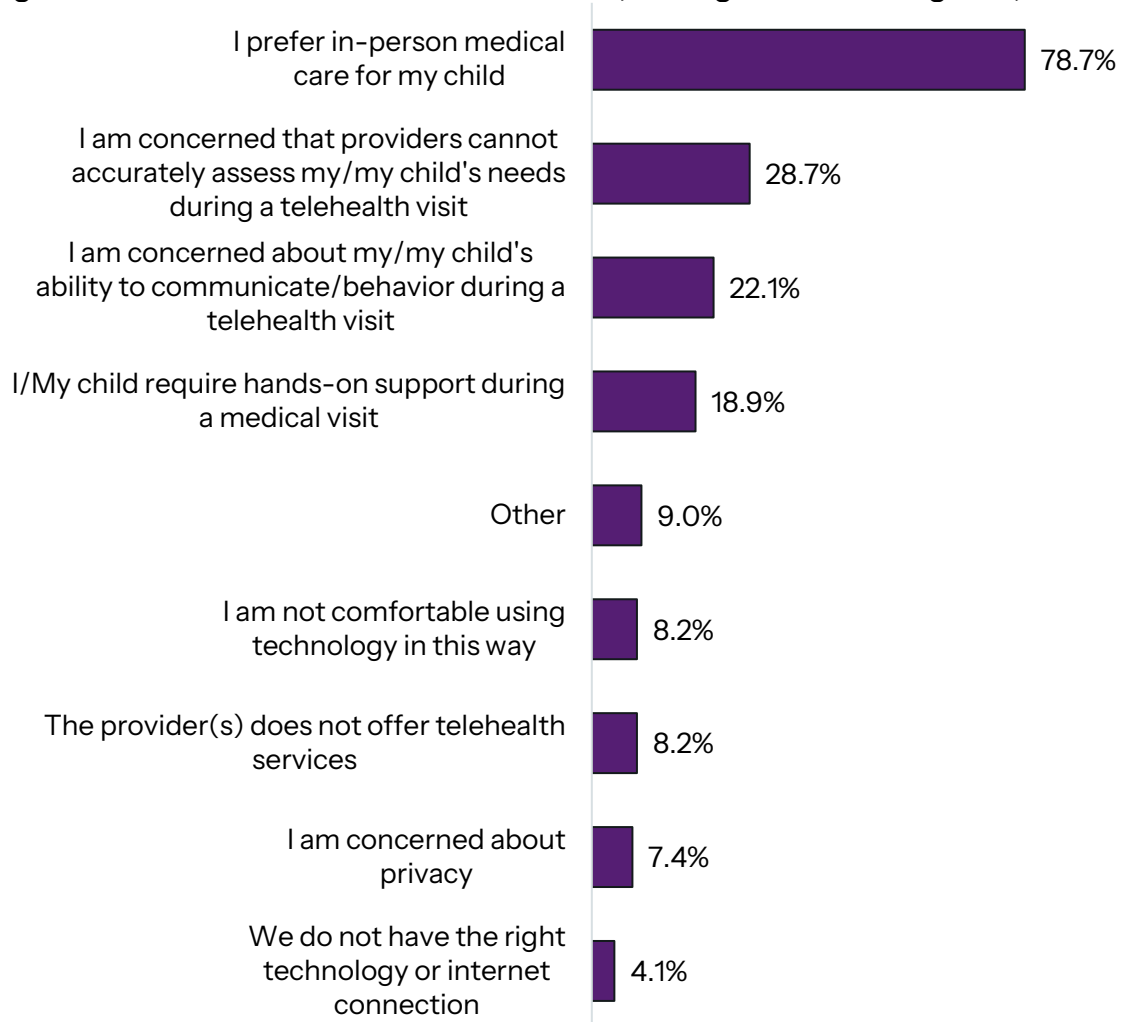
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 62. Levels of Satisfaction with Telehealth Use, among Parents/Caregivers, 2025 (n=263)**



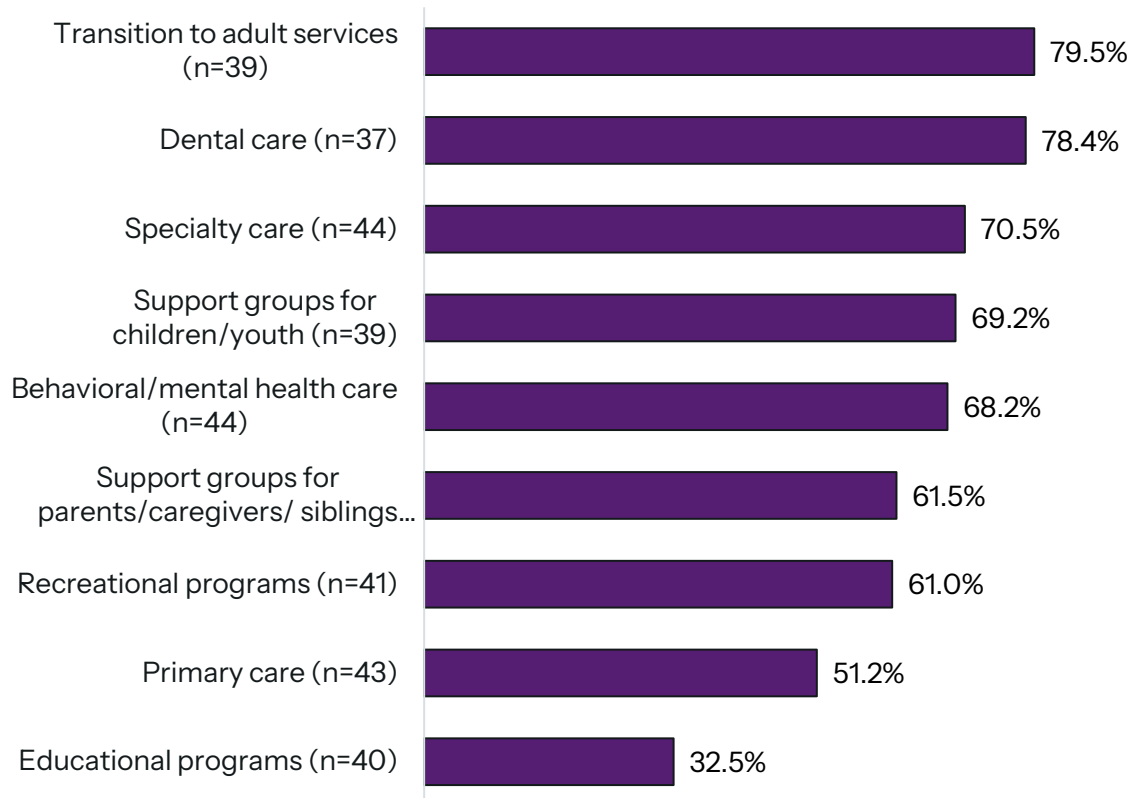
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 63. Reasons for Lack of Telehealth Use, among Parents/Caregivers, 2025 (n=126)**



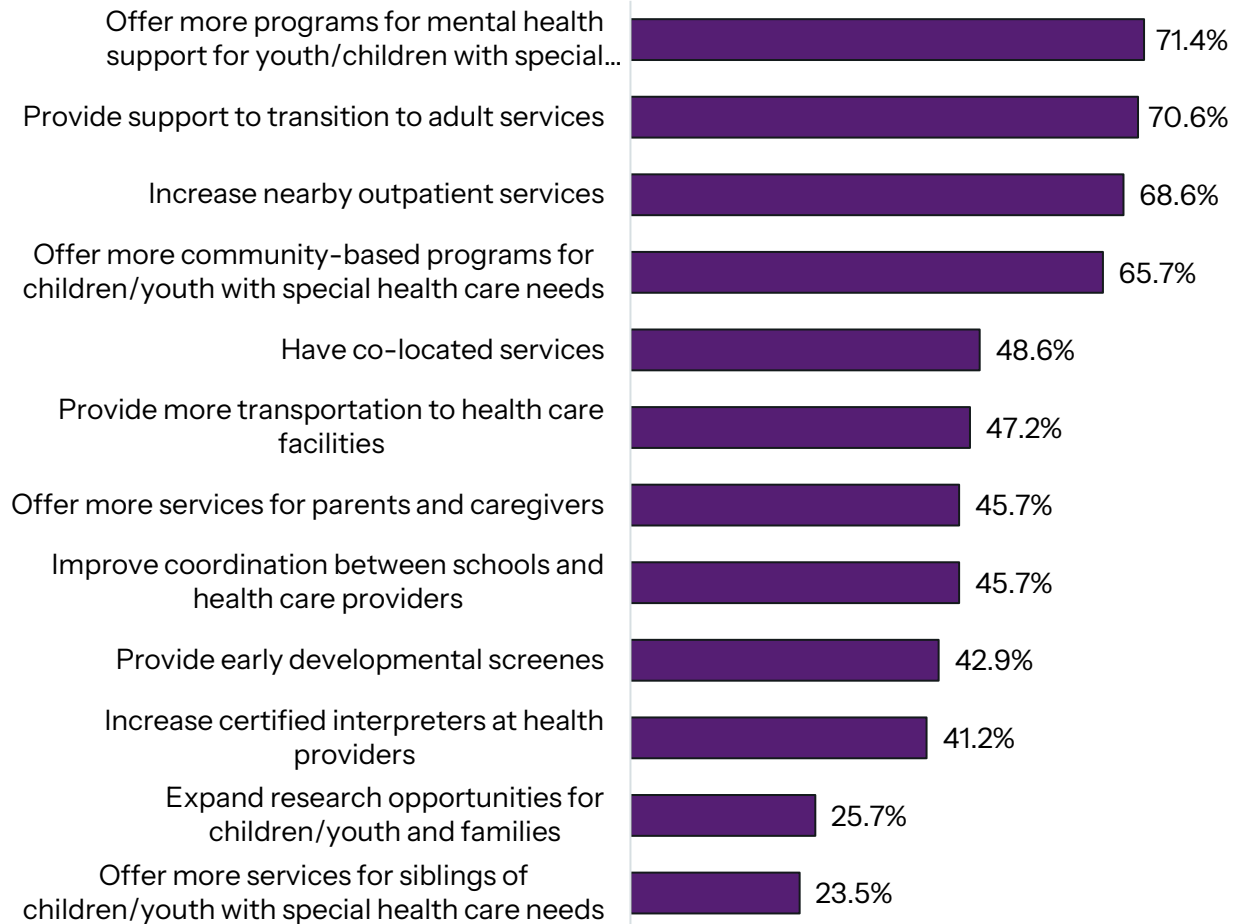
DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 64. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Healthcare Needs, among Other Respondents, 2025**



DATA SOURCE: CSH Community Health Needs Assessment Survey Data, 2025

**Figure 65. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Other Respondents, 2025**



## Appendix F: Resource Inventory

Name	Services	Locations	Website
Academy Learning Center	Center offers comprehensive programming for Students with Autism or Multiple Disabilities from ages 3-21	Monroe, TWP	<a href="https://www.escnj.us/domain/110">https://www.escnj.us/domain/110</a>
Alpha School	School provides educational, therapeutic and support services for students ages 5-21 with special needs	Jackson, NJ	<a href="https://alphaschool.com/contact-us/">https://alphaschool.com/contact-us/</a>
Archway Programs	Provide Step by Step is communication to creating partnerships with children and families to foster and encourage the development of infants and young children with developmental delays.	Atco, NJ	<a href="https://www.archwayprograms.org/contact-locations">https://www.archwayprograms.org/contact-locations</a>
ASAH	ASAH has served private special education schools and agencies in New Jersey ensuring highest standards services excellence for students and youth with disabilities.	Hamilton Square, NJ	<a href="https://www.asah.org/contact-us/">https://www.asah.org/contact-us/</a>
Association for Special Children and Families (ASCF)	ASCF is a community-based organization for families of children with disabilities	Hewitt, NJ	<a href="https://ascfamily.org/category/contact-us/">https://ascfamily.org/category/contact-us/</a>
Autism New Jersey	It is a non-profit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them.	Robbinsville, NJ	<a href="https://www.autismnj.org/connect/contact-us/">https://www.autismnj.org/connect/contact-us/</a>
Autism Speaks	Autism Speaks Enhances lives today and is accelerating a spectrum of solutions for tomorrow	Princeton, NJ	<a href="https://www.autismspeaks.org/contact-us">https://www.autismspeaks.org/contact-us</a>
Autism Spectrum Education	ASPEN provides families and individuals who lives are affected by Autism Spectrum Disorders and	Edison, NJ	<a href="https://aspennj.org/contact-aspen">https://aspennj.org/contact-aspen</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
Network (ASPEN)	Nonverbal learning disabilities		
Bethel Ridge	Sharing service by conducting classes for people with special needs to provide greater opportunities for kids	Basking Ridge, NJ	<a href="https://bethelridgenj.org/J3/">https://bethelridgenj.org/J3/</a>
Cambridge School	specialize in educating students with dyslexia, ADHD, and other language-based learning disabilities	Pennington, NJ	<a href="https://www.thecambridgeschool.org/contact-us/">https://www.thecambridgeschool.org/contact-us/</a>
Children's Center at Monmouth County	Serving the special need for children and their families	Neptune, NJ	<a href="http://www.ccprograms.com/ContactUs.aspx">http://www.ccprograms.com/ContactUs.aspx</a>
Community Access Unlimited (CAU)	Provide services for youth with intellectual and developmental disabilities	Elizabeth, NJ	<a href="http://www.caunj.org/?page_id=190">http://www.caunj.org/?page_id=190</a>
CPC Behavioral Health Care	CPC is a provider of choice for mental health, substance use and special education services for children and their families	Neptune, NJ	<a href="https://www.cpcbehavioral.org/neptune">https://www.cpcbehavioral.org/neptune</a>
Deron School of New Jersey, Inc	School prepares children with disabilities to lead successful, productive lives help to communicate in the community	Deron I Union, NJ Deron II Montclair, NJ	<a href="https://www.deronschool.org">https://www.deronschool.org</a>
Devereux Advanced Behavioral Health	Help to changes lives by unlocking and nurturing human potential for people living with emotional, behavioral or cognitive differences.	West Deptford, NJ	<a href="http://www.devereux.org/site/PageServer?pagename=centers">http://www.devereux.org/site/PageServer?pagename=centers</a>
Disability Rights New Jersey	Disability Rights New Jersey designated Protection and Advocacy agency for the State. advocates who wield the power of law to advance the human, civil, and legal rights of individuals with disabilities.	Statewide	<a href="https://disabilityrightsnj.org/">https://disabilityrightsnj.org/</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
Easterseals New Jersey	Non-profit organization that helped children and adults with disabilities and special needs, live better lives for nearly a century	East Brunswick, NJ	<a href="https://www.easterseals.com/nj/who-we-are/contact-us/">https://www.easterseals.com/nj/who-we-are/contact-us/</a>
Family Resource Network; NJWINS	The Family Resource Network is a comprehensive family-focused umbrella of organizations designed to meet the growing need for community-based programs and services to individuals and families with a variety of disabilities and chronic conditions through our three affiliate organizations (Autism Family Services of New Jersey; Caregivers of New Jersey and Epilepsy Services of New Jersey).	Statewide	<a href="https://njwins.org/about/">https://njwins.org/about/</a>
First Children Services	Life changing outcomes for Exceptional Kids. Educate students with multiple disabilities	Fanwood, NJ	<a href="https://www.firstchildrenservices.com/about-us/contact-us/">https://www.firstchildrenservices.com/about-us/contact-us/</a>
Greater Metro West ABLE'S	Local Jewish organizations	Essex, Morris, Somerset, Sussex and Union	<a href="https://www.greatermetrowestable.org/?utm_source=Kveller&amp;utm_medium=ABLE-resource-page&amp;utm_campaign=GMWAABLE">https://www.greatermetrowestable.org/?utm_source=Kveller&amp;utm_medium=ABLE-resource-page&amp;utm_campaign=GMWAABLE</a>
Harbor School	Providing an alternative program to the public-school districts for students with disabilities.	Eatontown, NJ	<a href="https://harborschool.com/contact-us/">https://harborschool.com/contact-us/</a>
Hawks wood School	Provides high quality special education services to children with complex, multiple disabilities, including autism	Eatontown, NJ	<a href="http://hawkswoodschool.net/contact-us/">http://hawkswoodschool.net/contact-us/</a>
Hudson Milestone	Provides in-home respite and early intervention services for families and children with developmental disabilities	Jersey City, NJ	<a href="http://www.hudsonmilestones.org/contact-us/">http://www.hudsonmilestones.org/contact-us/</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
Lardacein Network	It is a non-profit agency provides continuum of care including educational, therapeutic, social, residential and support services to infants, children and adults with complex physical and developmental disabilities or delays.	Wanamassa, NJ	<a href="https://www.ladacin.org">https://www.ladacin.org</a>
Need Quest	Local directory of special needs resources for parents, children and families in New Jersey	Westfield, NJ	<a href="https://needquest.com/contactus">https://needquest.com/contactus</a>
New Jersey Alliance for Children, Youth and Families	NJACF collaborate to ensure brighter futures for children, youth and families	Hamilton, NJ	<a href="http://njacyf.org/about-us">http://njacyf.org/about-us</a>
New Jersey Children System of Care (CSOC)	Provides volunteer services for children through Perform Care, Contracted Service Administrator for CSOC	Hamilton, NJ	<a href="https://www.mercerresourceset.org/about/about-new-jersey-s-children-s-system-of-care-csoc/">https://www.mercerresourceset.org/about/about-new-jersey-s-children-s-system-of-care-csoc/</a>
New Jersey Institute for Disabilities	NJID offers specialized facilities, programs and supports throughout the state of New Jersey for children and youth	Edison, NJ	<a href="https://www.njid.org/children-programs">https://www.njid.org/children-programs</a>
New Road Schools of New Jersey	Private school for students ages 5-21 years with developmental, learning, social, behavioral and language disabilities.	Perlin, NJ Somerset, NJ Lakewood, NJ	<a href="http://newroadschool.com/contact-nrs/">http://newroadschool.com/contact-nrs/</a>
NJ Children's System of Care Contracted System Administrator-Perform Care	Helping families across the state for Behavioral health, Intellectual/developmental disability services and substance use services	Robbinsville, NJ	<a href="https://www.performcarenj.org/index.aspx">https://www.performcarenj.org/index.aspx</a>
NJ Parent Link	NJ Parent Link, the State of New Jersey's Early Childhood, Parenting and	Statewide	<a href="https://www.nj.gov/njparentlink/">https://www.nj.gov/njparentlink/</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
	Professional Resource Center.		
NJ Register Ready	NJ Register Ready helps people with disabilities register their special needs with their county office of emergency management. This information is used by emergency planners for their disaster preparedness planning. This way when a disaster occurs, the county has properly prepared to meet the needs. If they don't know in advance the needs of their residents with disabilities, they will not be able to adequately prepare.	Statewide	<a href="https://nj211.org/initiative/nj-register-ready">https://nj211.org/initiative/nj-register-ready</a>
Noah's Ark Institute	Noah's Ark Institute is a non-profit organization and is a project of the National Association for Children with Autism	Fairfield, NJ	<a href="http://www.noahsarkinstitute.org/contact.html">http://www.noahsarkinstitute.org/contact.h tml</a>
Oakwood School	Private school for disabled children forms ages 11-21 years	Tinton Falls, NJ	<a href="http://oakwoodschoo.net/contact/">http://oakwoodschoo.net/con tact/</a>
Parents of Autistic Children (POAC) Autism Services	Help children and adults with autism to achieve their fullest potential by providing quality training, support and recreation	Brick, NJ	<a href="https://www.poac.net">https://www.poac.net</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
PerformCare New Jersey, New Jersey Children's System of Care	<p>PerformCare New Jersey is the contracted system administrator (CSA) for the State of New Jersey's Department of Children and Families, Children's System of Care (CSOC).</p> <p>PerformCare New Jersey is the single point of access to a wide array of behavioral health, intellectual and developmental disability services, as well as substance use treatment for youth and families throughout New Jersey. As the CSA, PerformCare New Jersey provides youth and their families with the services, resources, tools, and support they need to optimally participate in treatment within their homes, schools, and community settings. We provide the avenue for families to request clinically appropriate, needs-based services with a single phone call any time of the day or night.</p>	Statewide	<a href="https://www.performcarenj.org/">https://www.performcarenj.org/</a>
Princeton Child Development Institute (PCDI)	Providing Lifelong Services to People with Autism	Princeton, NJ	<a href="http://pcdi.org/early-intervention/">http://pcdi.org/early-intervention/</a>
Puzzle Place center For Autism	A Playful Approach to Serious Therapy	Freehold, NJ	<a href="https://thepuzzleplace.org/our-approach/">https://thepuzzleplace.org/our-approach/</a>
Rugby School	Provide a nurturing environment for special students to maximize their potentials while exploring their unique abilities	Wall Township, NJ	<a href="http://www.rugbyschool.org/our-school/about-rugby-school/">http://www.rugbyschool.org/our-school/about-rugby-school/</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
School of Children with Hidden Intelligence (SCHI)	SCHI provides educational and therapeutic services by certified professional staff to children with disabilities.	Lakewood, NJ	<a href="https://www.schischool.org/contacts/">https://www.schischool.org/contacts/</a>
Shore Center for Students with Autism	Program of the Bayshore Jointure Commission, is a New Jersey public school placement for students with special needs	Tinton Falls, NJ	<a href="https://www.theshorecenter.org/Page/1">https://www.theshorecenter.org/Page/1</a>
SPAN (Statewide Parent Advocacy Network)	Guide to developing and conducting an effective group	Newark, NJ	<a href="https://www.spanadvocacy.org">https://www.spanadvocacy.org</a>
Special Dragons	Providing exercise and self-defense programs for Special Needs Students	Northern New Jersey	<a href="http://www.specialdragons.us/index.html">http://www.specialdragons.us/index.html</a>
Special Kids Fun (SKF)	SKF is a unique charity alliance of social service organization, hospital, camps and schools caring for developmentally disabled children and youth.	Lakewood, NJ	<a href="http://www.specialkidsfund.org">http://www.specialkidsfund.org</a>
The Arc of New Jersey	State's largest organization advocating for serving children and adults with intellectual and developmental disabilities and their families. Local Chapters in all 21 Counties of NJ.	North Brunswick, NJ	<a href="https://www.arcnj.org/index.html">https://www.arcnj.org/index.html</a>
<i>The Arc of Bergen &amp; Passaic Counties</i>	Provides services for people with intellectual and developmental disabilities and their families	Hackensack, NJ	<a href="https://arcbp.org">https://arcbp.org</a>
<i>The Arc of Essex County</i>	Provides services for people with intellectual and developmental disabilities and their families	Livingston, NJ	<a href="https://arcessex.org">https://arcessex.org</a>
<i>The Arc of Hudson County</i>	Provides services for people with intellectual and developmental disabilities and their families	Hampton, NJ	<a href="https://archunterdon.org">https://archunterdon.org</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
<i>The Arc of Middlesex</i>	Provides services for people with intellectual and developmental disabilities and their families	North Brunswick, NJ	<a href="https://arc-middlesex.org">https://arc-middlesex.org</a>
<i>The Arc of Monmouth</i>	Provides services for people with intellectual and developmental disabilities and their families	Tinton Falls, NJ	<a href="https://arcofmonmouth.org">https://arcofmonmouth.org</a>
<i>The Arc of Morris County</i>	Provides services for people with intellectual and developmental disabilities and their families	Morris Plains, NJ	<a href="https://arcmorris.org">https://arcmorris.org</a>
<i>The Arc of Somerset</i>	Provides services for people with intellectual and developmental disabilities and their families	Manville, NJ	<a href="https://thearcofsomerset.org">https://thearcofsomerset.org</a>
<i>The Arc of Union</i>	Provides services for people with intellectual and developmental disabilities and their families	Springfield, NJ	<a href="https://arcunion.org">https://arcunion.org</a>
<i>The Arc, Ocean County Chapter</i>	Provides services for people with intellectual and developmental disabilities and their families	Lakewood, NJ	<a href="https://arcocean.org">https://arcocean.org</a>
<i>The Arc/Mercer, Inc</i>	Provides services for people with intellectual and developmental disabilities and their families	Ewing, NJ	<a href="https://arcmercercer.org">https://arcmercercer.org</a>
The Boggs Center on Developmental Disabilities	The Boggs Center is New Jersey's federally designated University Center for Excellence in Developmental Disabilities and part of Rutgers Robert Wood Johnson Medical School, Department of Pediatrics. Since its inception in 1983, The Center has emphasized a community-based, lifespan approach to meeting the needs of individuals with developmental disabilities and their families.	New Brunswick, NJ	<a href="https://boggscenter.rwjms.rutgers.edu/">https://boggscenter.rwjms.rutgers.edu/</a>
The Midland School	Helping students with disabilities reach their highest potential	North Branch	<a href="https://midlandschool.org">https://midlandschool.org</a>

<b>Name</b>	<b>Services</b>	<b>Locations</b>	<b>Website</b>
United Cerebral Palsy (UCP) of Hudson County	UCP provides services to people with disabilities and it helps them to improve the independence, productivity and quality of life.	Bayonne, NJ	<a href="http://ucpofhudsoncounty.org/about-us/">http://ucpofhudsoncounty.org/about-us/</a>
Youth Consultation Service (YCS)	YCS Sawtelle services provides educational, in-home, and residential care for individuals with intellectual and developmental disabilities from birth through adulthood.	Newark, NJ	<a href="http://www.ycs.org/index.php/contact-us/">http://www.ycs.org/index.php/contact-us/</a>

## **Appendix G. Outcomes and Results from Previous Implementation Plan**



# Community Health Needs Assessment

*Results of the Implementation Plan 2023*



# Introduction

In 2022, Children's Specialized Hospital (CSH) conducted and adopted its Community Health Needs Assessment (CHNA) which consisted of a community health needs survey of residents in our service area, a detailed review of secondary source data, a targeted survey for those living and working with special needs children and young adults, and meetings with stakeholders from a range of sectors. The CHNA is available for review at <https://www.rwjbh.org/documents/community-health-needs-assessment/CSH-CHNA-2022.pdf>.

Through the CHNA process, health needs priorities were chosen based on CSH's capacity, resources, competencies, and the needs specific to the populations it serves. The Implementation Plan addresses the manner in which CSH will address each priority need and the expected outcome for the evaluation of its efforts. The implementation plan which follows is based on the five selected priority areas\*:

- Access to health care services
- Access to transition services
- Access to other services (support groups, recreation, camps and clubs)
- Food insecurity
- Mental health and social emotional development

*\*The five focus areas do not represent the full extent of CSH's community benefit activities or its support of the community's health needs. Other significant needs identified through the CHNA include transportation, overweight/obesity, financial insecurity and educational access/special needs education. These needs may be better addressed by other agencies/organizations or deferred to another timeframe.*



# Priority 1: Access to Health Care Services

Goal	Strategy	Outcome
Develop 2-3 'Centers of Excellence' programs that will serve as a vehicle to achieve clinical, educational, innovation and growth to high need services.	1. Increase patient access to inpatient/outpatient services in selected areas by at least 6% through the development of 3 Centers of Excellence: Functional Neurological Disorders, Autism, and Brain Injury	The Chronic Pain Management COE generated a 10% increase in program access. The Brain Injury COE generated a 30% increase.
Collaborate with RWJBH leadership to streamline access referrals and strengthen intersystem care coordination	1. Develop at least 2 hard-wired RWJBH system-wide communication pathways for increasing referral access by 10%	We developed at least 2 hardwired RWJBH system-wide communication pathways for increasing access referrals.



# Priority 1: Access to Health Care Services

Goal	Strategy	Outcome
In conjunction with RWJBH, new outpatient centers in high need communities of East Brunswick Ambulatory Center and develop a new ambulatory site in Newark	<ol style="list-style-type: none"> <li>1. Complete East Brunswick outpatient center by 12/31/23</li> <li>2. Further discussion with system regarding potential collaboration for a Newark outpatient center</li> </ol>	<ol style="list-style-type: none"> <li>1. East Brunswick Outpatient Center opened in January 2024</li> <li>2. We continue to work with the system to explore the opening of a new Newark Outpatient Center</li> </ol>
Effectively distribute patients with select conditions (e.g., ADHD) to appropriate care setting (e.g., telehealth) and provider (e.g., generalist, group therapy)	<ol style="list-style-type: none"> <li>1. Reduce wait time for ADHD and anxiety</li> <li>2. Expand both Chronic Illness program and Palliative Care program to at least 1 outpatient site</li> </ol>	<ol style="list-style-type: none"> <li>1. We explored a model to fast-track internal referrals between psychology, OT, and developmental. However, with our transition to Epic we were unable to implement the model which required building additional appt. types for internal referrals. We will continue to explore our options now that we're up on Epic.</li> <li>2. The decision was made not to expand these services to outpatient sites at this time. However, expansion is occurring in other ways including physicians obtaining NY licensure to broaden access to NY based patients in addition to developing more disease-specific programs including asthma, diabetes, cystic fibrosis, sickle cell and others.</li> </ol>



## Priority 2: Access to Transition of Care Services

Goal	Strategy	Outcome
Increase awareness of existing resources to support the need for transition of care services	1. Create and update as applicable the CSH Transition of Care webpage	A webpage was created dedicated to sharing resources around transitions of care in 2023.
Create a CSH Transition of Care program	<ol style="list-style-type: none"> <li>1. Form a Transition of Care program workgroup</li> <li>2. Create and complete SI documentation for approval</li> </ol>	A Transition of Care program workgroup was developed that presented SI documentation for approval. Ultimately, the decision was made to move forward in another direction but we continue to explore lifespan program alternatives and relationships with adult providers in the RWJBH system.



# Priority 3: Access to Other Services (support groups, recreation, camps & clubs)

Goal	Strategy	Outcome
Expand requested community recreation to geographies of high need (e.g., Toms River)	1. Enhance community recreation program offerings in the Toms River/Ocean County area through expanded relationship with RWJBH Field of Dreams and new CSH/FOD Program Director position	Community recreation programs were expanded primarily at the RWJBH Field of Dreams in Toms River as this facility provided a consistent location and utilization accessible park and recreation amenities. In 2023, 24 additional programs were offered by CSH at this facility to more than 750 participants in Ocean County. This continued to grow through 2024 and presently 2025.



# Priority 4: Food Insecurity



Goal	Strategy	Outcome
Expand social determinants of health programs through targeted Center for Discovery, Innovation and Development (CDID) collaboration efforts	<ol style="list-style-type: none"><li>1. Increase the SDOH screenings from 2022 baseline of 16,500 by 1,500 (target) or 3,000 (max) by 12/31/23</li><li>2. Launch FindHelp platform by 4/30/23</li><li>3. Form a Health Equity advisory committee with stakeholders and members representing communities we serve by 6/30/23</li></ol>	<ol style="list-style-type: none"><li>1. We exceeded this goal. In 2023, we completed 21,136 screenings. By end of 2024, we had screened over 25,000.</li><li>2. We launched the CSHConnect Platform via FindHelp in August 2023.</li><li>3. Established the Healthy Equity Advisory Committee and held the first meeting in November 2024.</li></ol>



# Priority 5: Mental Health & Social Emotional Development



Goal	Strategy	Outcome
Grow and build new programming to meet the expanding need for behavioral health services focusing on early childhood illness and non-crisis care (ABA partnership, anxiety)	<ol style="list-style-type: none"><li>1. Implement an ABA program by 12/31/23</li><li>2. In order to facilitate caring for the comprehensive behavioral health needs of patients most effectively, Psychology &amp; Psychiatry will explore the feasibility and utility of a dyadic evaluation to assess and treat a certain diagnostic group, such as OCD or mood disorders, by the end of Q2. If a pilot is indicated, will implement by the end of Q3</li></ol>	<ol style="list-style-type: none"><li>1. We grew the CSH RUCARES ABA Severe Behavior Program and Intensive Feeding Program in 2023 and 2024. Additionally, we established a partnership for ABA services across NJ &amp; nationally in 2024.</li><li>2. A dyadic evaluation was trialed and piloted but ultimately determined to not be effective.</li></ol>

