# Children's Specialized Hospital Community Health Needs Assessment

2022

PREPARED BY
HEALTH RESOURCES IN ACTION

Children's Specialized Hospital®
An RWJBarnabas Health facility

# Acknowledgements

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The Children's Specialized Hospital Community Health Needs Assessment was developed with the guidance of numerous partners that provided oversight and input throughout the process as part of an Advisory Committee. This Committee was chaired by Megan Granozio. Advisory Committee members included:

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# Executive Summary

## Introduction

In 2022, 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 health care needs and their families in New Jersey and prioritize those needs to inform strategies to improve community health.

## Context

This CHNA was conducted during an unprecedented time period due to the COVID-19 pandemic and the national movement for racial justice. The COVID-19 pandemic coincided with the activities of this assessment and impacted both the CHNA data collection process, as well as topics and concerns that residents raised in focus groups and key informant interviews.

## Methods

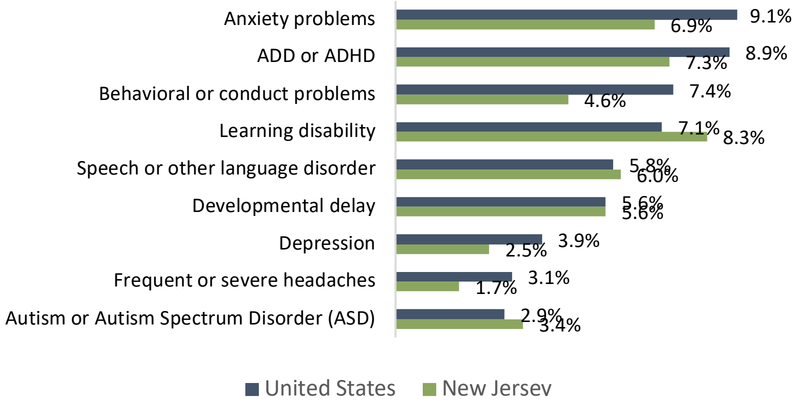
The 2022 CSH CHNA utilized a comprehensive data collection approach focused on the social determinants of health and applying a health equity lens. The CHNA process used a mixed-methods, participatory approach that engaged agencies, organizations, and those with special health care needs and their families 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. Methods of data collection included:

- Reviewing existing data on social, economic, and health indicators in New Jersey.
- Reviewing results of a general community survey (2,311 participants with at least 1 child in household)
- Conducting a targeted survey for those living and working with special needs children and young adults (996 participants).
- Facilitating two virtual focus groups with nine parents and caregivers of children and youth with special health care needs who participate in CSH's Family Advisory Council and three youth with special health care needs participating in CSH programming.
- Conducting nine key informant interviews with stakeholders from a range of sectors.

## Findings

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

**Percent Children Aged 3-17 Years with Current or Lifelong Condition, by United States and New Jersey, 2019-2020**



DATA SOURCE: 2019-2020 National Survey of Children's Health

### *Population Characteristics*

- **Demographics**. The total population of New Jersey is slightly under 9 million and approximately 30% of this population is under age 24. A majority of residents self-identify as non-Hispanic White (54.7%), followed by residents who self-identify as Hispanic (20.4%) and non-Hispanic Black

(12.6%).[1] CSH has locations in several of New Jersey's most racially and ethnically diverse counties including Essex, Hudson, Passaic, and Union.

- **Population of Children with Special Health Care Needs**. About 18% of children under age 18 in New Jersey have special health care needs.[2] Learning disabilities, ADD/ADHD, and anxiety problems are the most common special health care conditions among children ages 3-17 in New Jersey.

*Community Social and Economic Environment*

- **Community Strengths and Assets.** CHNA participants stated that New Jersey has many resources to support children with special health care needs and their families including health care services, advocacy and education organizations, and referral and coordinating agencies. State and local organizations, including schools and community-based nonprofits, offer sports, recreational, education, and transition programs for children and youth.

- **Education.** Data indicate that in 2019, 231,842 students ages 6 to 21 (13.2%) received special education services in New Jersey.[3] In New Jersey, school districts provide a variety of services to support students including occupational therapy (OT), physical therapy (PT), and speech, among others; however, assessment participants discussed that navigating services provided by school districts can be a source of tension between school staff and parents. The COVID-19 pandemic reduced access to school-based services for children with disabilities, resulting in regression in communication and education skills for some and substantial stress for parents.

- **Employment and Workforce.** Unemployment rates in New Jersey over the past decade had been trending downward prior to the COVID-19 pandemic, after which rates rose substantially. Families of children with special health care needs discussed facing challenges related to employment. One quarter of parent/caregiver community survey respondents reported that they or a family member lost employment due to the pandemic.

- **Income and Financial Security.** While median household income in New Jersey is high ($106,937), slightly over 10% of families with children under age 18 live below the poverty line.[4] Parents of special needs children reported economic challenges including loss of family income if one parent needs to stay home with a special needs child, and additional financial burdens such as transportation, equipment, and additional services and care. While support is available to help families, participants discussed how not all qualify and administrative barriers create challenges to accessing benefits.

> *"When you look at the financial aspect, it does cost quite a bit more compared to typical children. Also, I think about the families that sort of fall in the middle – not qualifying [for benefits] to meet all their needs."*- Focus group participant

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[1] U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

[2] National Survey of Children's Health, 2019-2020. NCSH defines Children and Youth with Special Health Care Needs (CYSHCN) as "children under age 18 who are at increased risk of 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."

[3] U.S. Department of Education, IDEA Section 618 Data Tables, Fall 2019 as cited by Annual Disability Statistics Compendium.

[4] U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020.

- **Food Access and Food Insecurity.** The proportion of children who are food insecure in New Jersey increased from 9.9% to 16.1% over the two years of the pandemic. Data from the CSH Social Determinants of Health (SDOH) screening survey indicate that about 2 in 10 CSH families were identified as food insecure in the first quarter of 2022.[5]

- **Housing.** Housing costs can be a burden for families, especially given the cost of living in New Jersey. American Community Survey data indicate that 46.2% of homeowners and 62.2% of renters spend 25% or more of their household income on housing.[6] Data from the CSH SDOH screening survey identified that 3.8% of CSH families were without steady housing and another 9.7% were concerned with losing their current housing.[7]

- **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.

- **Discrimination and Racism.** While challenges related to discrimination and racism were not prevalent themes in interviews and the parent focus group, some parents reported language barriers to accessing health care. In focus group and interview discussions, several parents and caregivers shared that they were felt that they were treated differently or disrespected because their children had special needs.

*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 health care needs are overweight (20.9%) than other children (6.1%).[8] Fewer special needs children engage in regular physical activity.

- **Behavioral Health.** As in past CHNAs, mental health was identified as a challenge for families with special needs children in 2022, exacerbated even more so by the pandemic. Participants discussed that barriers to accessing mental health services include waitlists, limited insurance coverage for services, and lack of providers willing to take new patients or accept some insurance. Lack of mental health services for young adults who have aged out of pediatric services is also a challenge. The quality of mental health care for children with special health care needs was a concern as some providers did not seem as adept in distinguishing between mental health issues and behaviors associated with a neural development diagnosis. Mental health services for parents and siblings of children with special needs who deal with substantial stresses is often overlooked but needed.

> *"Patients with mental health needs need to see a professional in a timely manner. A child's status can significantly decline or decompensate very quickly when they are not able to get an appointment with a psychologist."* – Community survey respondent

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[5] Data collected from 2,297 screenings, conducted January 1 through March 31, 2022.

[6] U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020.

[7] Data collected from 2,297 screenings, conducted January 1 through March 31, 2022.

[8] National Survey of Children's Health, 2019-2020.

- **Environmental Health**. About 0.6% of children in the state of New Jersey had elevated blood lead levels between 2016 and 2020.

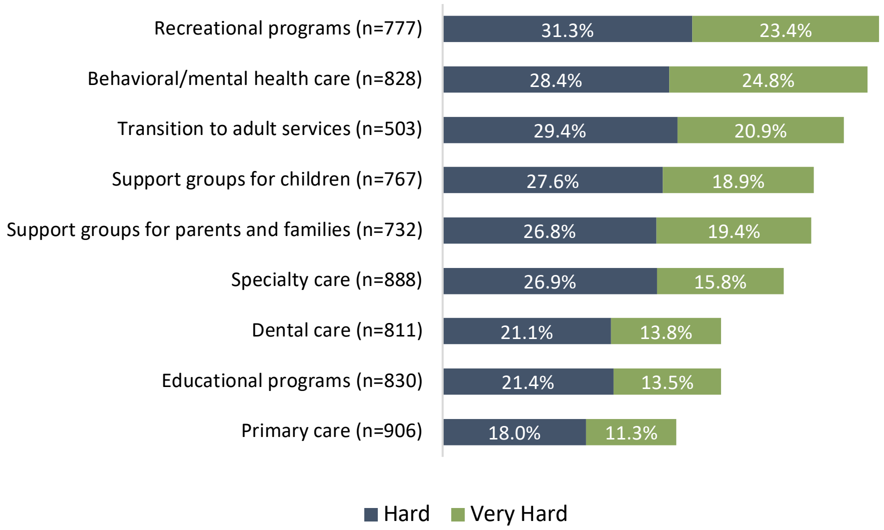
- **Infectious and Communicable Disease**. As of June 2022, there were 251.6 cases per 100,000 population in New Jersey. About 78% of New Jersey residents over the age of 5 were fully vaccinated as of July 2022.

- **Maternal and Infant Health.** About 8% of births in New Jersey in 2016-2020 were to babies weighing under 2500 grams (low birthweight). In 2019, 63.1 births per 10,000 in New Jersey had neonatal abstinence syndrome (NAS).

*Access to Services*

CSH survey respondents identified recreational programs, behavioral/mental health care, and transition services as hardest to access for children with special health care needs, similar to CHNA survey results from 2019. Recreational programs were the most difficult to access, perhaps a reflection of the fact that many programs and services were cut during the pandemic. Challenges accessing recreational and behavioral/mental health programs were the top two concerns for non-Hispanic Asian, non-Hispanic White, and Hispanic parent/caregiver respondents, while finding programs to support transition to adult services was the top challenge for Black respondents and those who identified as other or multiracial. The following provides a deeper dive on assessment participants' concerns around accessing services.

**Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Health Care Needs, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

- **Access to Health Care Services.** Parents/caregivers cited numerous barriers to accessing health care for their special needs children including difficulty scheduling appointments quickly, insufficient information about available services, and lack of nearby providers and evening and weekend services. Shortages of developmental behavioral pediatricians and long wait times for appointments for pediatric surgery and therapies (OT, PT, speech) were frequently mentioned. Finding health care providers for transition-age young adults is particularly difficult as these patients are no longer able to access services through children's hospitals. Additional challenges shared by parents/caregivers included health care professionals without sufficient training to work with patients with more complex health challenges and lack of care coordination across health care, education, and other systems.

- **Use and Perceptions of Telehealth**. Parent/caregiver survey respondents largely reported satisfaction with telehealth services; over half reported that they would be "extremely" or "very" likely to use telehealth for their child with special health care needs in the future. Those who reported positive experiences with telehealth cited the convenience of not having to travel and the ability to better schedule around work obligations. For some children, however, interacting on a screen is difficult; some families face challenges accessing technology.

- **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 health care needs, including sports and recreation programs for children and support and educational programs for parents/caregivers, yet these can be difficult to access.  Participants cited barriers such as lack of promotion of available programs and services, need to travel long distances to participate, limited eligibility to "high functioning" children, and cost. Accessing parent programs can be hampered by lack of childcare and language barriers. Finding services to support transition to adulthood was reported to be especially challenging. Planning for these next steps is critical but accessing information about what to do can be difficult. While school districts provide a variety of supports for transition at age 21, after students leave the school system, fewer opportunities are available and in many cases young people need to start over with new services and social and recreational programs for their age group.

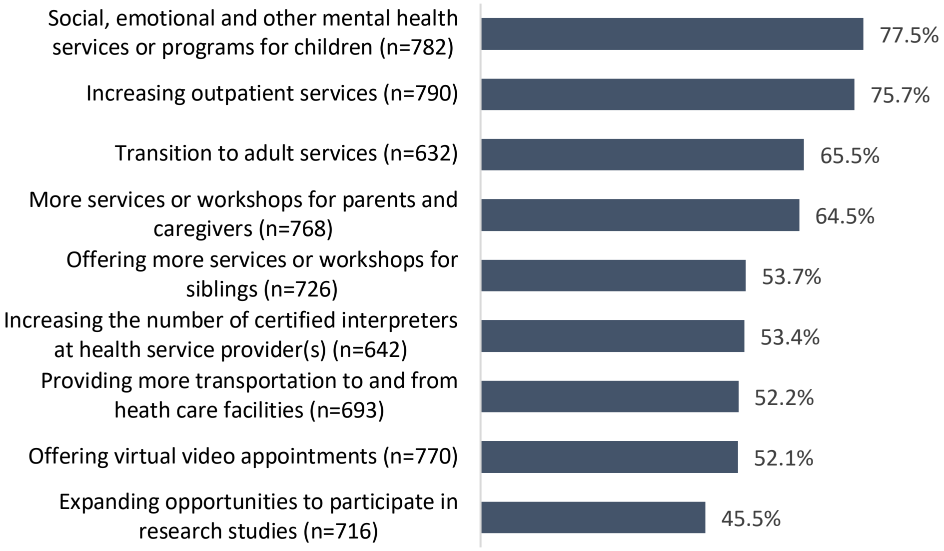
> "*[Parents] are just living day-to-day. And then you've got that cliff [of transition age]. It appears and you're gonna go falling off if you haven't had some steps in place*." – Key informant interviewee

*Community Vision and Suggestions for the Future*

CSH survey respondents identified social, emotional, and other mental health services, outpatient services, transition to adult services, and workshops for parents and caregivers as highest priority, as in 2019. Suggested high priority programs and services were largely similar across all demographic groups with social, emotional, and other mental health services and outpatient services identified as the top two priorities.

Focus group and interview participants discussed their vision in more detail below:

**Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

- **Expanding and Strengthening Healthcare Services.** Given the connection between early diagnosis and care to better outcomes, participants and survey respondents suggested expanding the number of providers able to conduct assessments. They also identified a need for more OT, PT, and speech therapy providers, closer to home and offering evening and weekend hours. They additionally suggested training and mentoring to enhance the competency and sensitivity of the healthcare workforce, including office staff, to work with children and young adults with special healthcare needs. Enhanced coordination/case management services were also seen as important, with a goal of identifying needs and connecting families to organizations that address the social determinants of health.

- **Expanding Mental Health Services**. Survey respondents as well as interviewees identified a need for more psychologists and psychiatrists for children with special health care needs as well as more board-certified behavioral analysts (BCBA) and those able to provide therapies such as ABA, Cognitive Behavioral Therapy (CBT), DIR®/play, and group therapy. Increasing the number of mental health providers accepting Medicaid was also suggested.

- **Increasing Affordable and Accessible Programs for Children and Youth**. CHNA participants suggested more peer social groups to provide special needs children and youth a sense of belonging and support socialization. Expanded recreation and sports programs, including camps and art programs, were also suggested. Parents saw a need for more free or lower cost programs to ensure they are accessible to all special needs children. They also advocated for programs that are inclusive of children and youth with range of abilities, not just those who are higher functioning.

- **Expanding Transition Services**. Parents advocated for more support to help them plan for their children's' future including workshops and presentations. Hands-on support, such as from social workers and care coordinators, was also suggested. 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. A theme in many conversations about transition to adulthood was the importance of programs to support workforce participation including exposure to employment pathways, job supports, volunteer opportunities, life skills training, and transportation. Finally, parents and young adults advocated for more peer groups and recreational and other programs for older youth, with a focus on opportunities to socialize.

- **Expanding supports for families**. Supporting families of children with special health care needs was a frequent topic of conversation in interviews and the parent focus group and was identified as high priority in the community survey. Suggestions included parent workshops, parent and sibling support groups, and respite services.

- **Ensuring Information about Programs and Services Reaches Families**. Parents/caregivers stressed the importance of programs close to home and noted that information about programs needs to reach families of all types across New Jersey. They suggested that information about programs be available in multiple languages and be shared in different formats, including social media, email, television and radio, and flyers.

- **Focusing on the Social Determinants of Health**. CHNA participants provided suggestions to address transportation barriers faced by some families including expanding existing transportation services such as hospital shuttles and offering reimbursement/vouchers for transportation. They also suggested continued partnership between hospitals and community services organizations to ensure that families' other needs that affect health care are addressed.

- **Advocacy for Systems Change**. Although not a prominent theme, a couple of parent focus group members shared that they would like to see more training to help parents/caregivers understand and be advocates for their children as they work with education, health, and benefits systems. At the same time, interviewees also suggested that CSH could play a greater role and have more of a presence statewide by participating in statewide coalitions and groups.

**Key Themes**
Several overarching themes emerged from this 2022 assessment.

- ***New Jersey has many assets for families with children with special health care needs and their families, yet there are barriers to accessing these***. While New Jersey has many resources to support children with special health care needs and their families, lack of awareness of these is a barrier to access. Families with special needs children seeking health and mental health services additionally face challenges such as too few providers, long wait times for appointments, lack of evening and weekend hours, limits on insurance coverage, and cost. Particularly challenging are finding therapists, mental health providers, and subspecialists. Limited provider experience working with children and youth with special health care needs is also a concern that 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 narrow eligibility, and may be costly. Overall, assessment participants perceived that there were limited programs and services to support young people with special needs as they transition to adulthood.

- ***The COVID-19 pandemic and current economic challenges have had substantial impact on the lives and the physical and mental health of children with special health care needs and their families.*** The COVID-19 pandemic has affected all sectors of life, including financial and mental well-being, education, access to healthcare, and food security. Families were isolated and disconnected from services, especially early in the pandemic, and 24/7 caregiving created additional stress for many families of special needs children. In addition to educational loss, children with disabilities were not able to access services they received in school at home during the height of the pandemic which has negatively affected student progress.

- ***Increasing access to key 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. Therapies located closer to home, through satellite locations, were seen as important. Participants also cited a need for more mental health providers such as psychiatrists and psychologists and those with experience in ABA, CBT, and DIR®/play therapies. Expanding the workforce of professionals able to conduct developmental assessments was also suggested. Enhancing the competency of the healthcare workforce to work with children and young adults with special healthcare needs and their families is also needed. Telehealth is one option to address some of these constraints but does not work for all patients.

- ***Opportunities exist to expand social and recreational programs for children with special health care needs, and support for their parents, caregivers, and siblings.*** Assessment participants frequently requested more programs, such as sports, arts, and recreation and camps, and opportunities for children and youth with special health care needs to socialize with their peers. Many also noted that parents/caregivers and siblings of children with special health care needs could benefit from additional educational and emotional support, including workshops and support groups, and from respite care. Addressing barriers such as location and cost is also important.

- ***Participants see a need for more transition programs***. Transition to adulthood is an overwhelming time for parents with special needs children and requires planning and support. Assessment participants suggested more information to parents about transition planning and support to undertake this and a greater role of specialty pediatricians in supporting the transition from pediatric to adult health care systems. For young people, they suggested expanded work opportunities and job support through exposure to employment pathways and job supports, volunteer opportunities, life skills training, socialization/peer programs, and support for transportation.

- ***Consideration should be given to transportation support and continued connection to services that address the social determinants of health***. 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. Building on community-hospital partnerships on- and off-site to address the social determinants of health including food insecurity and legal concerns was also suggested. Ensuring information about these programs and services are accessible to all families is essential.

**Conclusion**

Through a comprehensive and iterative assessment process that included gathering community input from residents and stakeholders, feedback from a community survey, and quantitative surveillance and secondary data, nine initial issue areas were identified as key community needs for the region CSH serves. These included (in no particular order):

- Educational access and special education needs
- Financial insecurity
- Food insecurity
- Transportation
- Overweight/obesity
- Mental health and social emotional development
- Access to health care services
- Access to transition services
- Access to other services (support groups, recreation, camps and clubs)

After a prioritization process with the Advisory Committee and other stakeholders, key priority areas for CSH will include mental health and social emotional development, access to transition services, access to health care services, food insecurity, and access to other services (support groups, recreation, camps and clubs) as it also considers its existing expertise, capacity, and experience during the development of its implementation plan in 2023.

# Introduction

**Community Health Needs Assessment Purpose and Goals**
A community health needs assessment (CHNA) is a systematic process to identify and analyze community health needs and assets, prioritize those needs, and then implement strategies to improve community health. In 2022, 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, long term care facilities, diagnostic imaging centers, a clinically integrated network and collaborative accountable care organization.

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 vision is a world where all children can reach their full potential. CSH's mission is to be the preeminent provider of specialized healthcare to infants, children, and young adults. CSH provides services in fifteen different New Jersey locations, across ten counties including Atlantic, Essex, Hudson, Mercer, Middlesex, Monmouth, Ocean, Passaic, Somerset, and Union Counties. During 2021, CSH cared for approximately 115 patients daily and provided over 182,000 visits of early intervention, physician and outpatient services.

This assessment process builds off of previous assessment and planning processes conducted by Children's Specialized Hospital and its affiliated network. See Appendix F for a description of the hospital's community health activities accomplished and their impact since 2019.

In early 2021, RWJBH hired **Health Resources in Action (HRiA**), a non-profit public health consultancy organization, to provide support, help facilitate, and conduct data analysis for the CHNAs across the system. HRiA worked closely with CSH and the CSH CHNA Advisory Committee to support the CSH CHNA.

The CSH CHNA aims to gain a greater understanding of the issues that residents—particularly children, youth, and young adults with special health care 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 2022 CSH needs assessment process, which was conducted between March-September 2022.

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 health care needs and their families in the service area overall and its sub-populations within their social context,
- Engage the community to help determine and prioritize community needs and social determinant of health needs, and
- Fulfill the IRS mandate for non-profit hospitals.

**Area of Focus**

This CHNA process aims to fulfill multiple purposes for a range of stakeholders. 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.

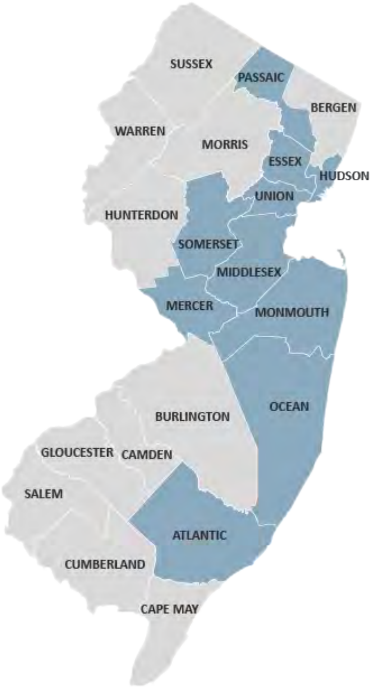
**Context for the Community Health Needs Assessment**

This CHNA was conducted during an unprecedented time, given the COVID-19 pandemic and the national movement for racial justice. This context had a significant impact on the assessment approach and content.

*COVID-19 Pandemic*

The novel coronavirus (COVID-19) pandemic coincided with the activities of this assessment and impacted both the CHNA data collection process and topics, as well as concerns that participants put forth during discussions in focus groups and interviews. In March 2022, at the beginning of this CHNA process, the COVID-19 pandemic had already been in effect for about two years. Logistically, the pandemic impacted the feasibility of convening in-person groups for the CHNA (e.g., Advisory Committee, focus groups, etc.) and the availability of key stakeholders and community members to participate in CHNA activities, given their focus on addressing immediate needs. Consequently, all data collection and engagement occurred in a virtual setting (e.g., telephone or video focus groups, interviews), and engagement of residents and stakeholders was challenging. (A more detailed description of this engagement process may be found in the Methods section, and COVID-19 data specific to this service area is provided in the Infectious and Communicable Disease section of this report.)

**Figure 1. CSH CHNA Focus Area Map**



Substantively, during the CHNA process, COVID-19 was and remains a health concern for communities and also has exacerbated underlying inequities and social needs. The pandemic brought to light both the capabilities and gaps in the healthcare system, the public health infrastructure, and social service networks. In this context, an assessment of the community's strengths and needs, and in particular the social determinants of health, is both critically important and logistically challenging. This CHNA should be considered a snapshot in time, which is consistent with public health best practices. Moving forward the community should continue to be engaged to understand how identified issues may evolve and what new issues or concerns may emerge over time.

*National Movement for Racial Justice*

Over the past few years, sparked by the national protests for racial equity amidst the killings of George Floyd, Ahmaud Arbery, Breonna Taylor, Tony McDade, and many others, national attention was focused on how racism is embedded in every system and structure of our country, including housing, education, employment, and healthcare. This context impacted the content of the CHNA, including the design of data collection instruments and the input that was shared during interviews and focus groups. While racism and oppression have persisted in this country for over 400 years, it is important to acknowledge the recent focus on these issues in 2022 in the form of increased dialogue, locally and nationally, as context for this assessment.

## Methods

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

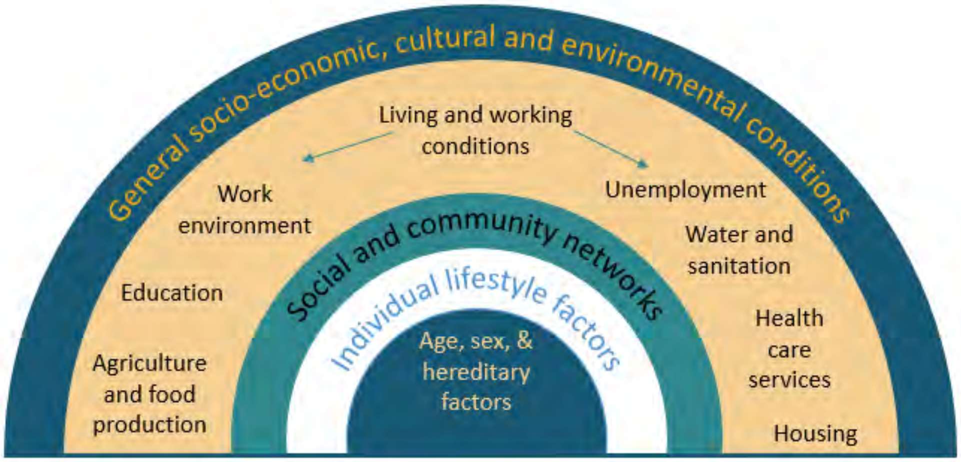
### Social Determinants of Health Framework

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 is about more than delivering quality healthcare to residents. Where a person lives, learns, works, and plays all have an enormous impact on health. Health is not only affected by people's genes and lifestyle behaviors, but by upstream factors such as employment status, quality of housing, and economic policies. Figure 2 provides a visual representation of these relationships, demonstrating how individual lifestyle factors, which are closest to health outcomes, are influenced by more upstream factors, such as employment status and educational opportunities.

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



DATA SOURCE: World Health Organization, Commission on the Social Determinants of Health, Towards a Conceptual Framework for Analysis and Action on the Social Determinants of Health, 2005.

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, much of this report is dedicated to discussing the social, economic, and community context in which residents live. We hope to understand the current health status of residents and the multitude of factors that influence health to enable the identification of priorities for community health planning, existing strengths and assets upon which to build, and areas for further collaboration and coordination.

*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 in the U.S.

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

### Approach and Community Engagement Process

The CHNA aimed to engage agencies, organizations, 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.

*RWJBH System Engagement*

This CHNA is part of a set of CHNAs being conducted across the entire RWJBH system. Each of these CHNAs will use a consistent framework and minimum set of indicators but the approach and engagement process are tailored for each community. A Systemwide CHNA Steering Committee was convened twice, in early and late June 2021. This Steering Committee provided input and feedback on major data elements (e.g., secondary data key indicators, overall Table of Contents) and core prioritization criteria for the planning process. A list of Systemwide CHNA Steering Committee members can be found in Acknowledgments section.

*Advisory Committee Engagement*

The CSH CHNA Advisory Committee was engaged throughout this process. The Committee met virtually in March 2022 to launch the CHNA process and provided ongoing feedback over email on CHNA methodology, data collection instruments (e.g., focus group and interview guides and 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).

*Community Engagement*

Community engagement is described further below under the primary data collection methods. Capturing and lifting up voices a range of voices, especially those not typically represented in these processes, was a core component to this initiative. It should be noted that, due to the COVID-19 pandemic, the community engagement for this CHNA occurred virtually. Additionally, while the CHNA aimed to engage a cross-section of individuals and to be inclusive of traditionally under-represented communities, outreach was challenging given the pandemic and competing priorities. Nevertheless, by engaging the community through multiple methods, this CHNA aims to describe community strengths and needs during this unique time.

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

Secondary data are data that have already been collected for another purpose. Examining secondary data helps us to understand trends, provide a baseline, and identify differences by sub-groups. It also helps in guiding where primary data collection can dive deeper or fill in gaps.

Secondary data for this CHNA were drawn from a variety of 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 are typically presented as frequencies (%) or rates per 100,000 population. It should be noted that when the narrative makes comparisons between towns, by subpopulation, or with NJ overall, these are lay comparisons and *not* statistically significant differences.

It should be noted that for most social and economic indicators, the U.S. Census American Community Survey (ACS) 5-year (2016-2020) aggregate datasets were used over the one-year datasets, since many of the towns in the service area are smaller in population size. Since the ACS uses a probability sampling technique, using the five-year aggregate dataset over the one-year data provides a larger sample size and more precision in its estimates.

In addition to data from surveillance systems, this report also contains data collected by CSH. The first are data about social determinants of health 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. CSH also collects community-level data through its Community Developmental Screening Program. CSH uses the Ages & Stages® questionnaire to screen children under age 3 in the community who are not CSH patients. These data are used to identify children to be referred for additional evaluation. Follow-up data are collected to determine if an appointment has been scheduled. Prior to COVID, data were collected from children in preschools, day cares, libraries, and community clinics in underserved communities. Since COVID, this screening has been offered virtually.

This 2022 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**

*<u>Qualitative Discussion: Key Informant Interviews and Focus Groups</u>*

*Key Informant Interviews*

A total of nine key informant interview discussions were completed by Zoom or telephone. 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, transition services, health, mental, legal services, food, advocacy, and education. See Appendix A for the list of organizations engaged through key informant interviews and Appendix B for the key informant interview guide.

### *Focus Groups*

A total of 12 community residents participated in two virtual focus groups. One group (nine participants) included parents and caregivers of children and youth with special health care needs who participate in CSH's Family Advisory Council. The other group (three participants) included youth with special health care needs participating in CSH programming.

Focus groups were up to 45-minute semi-structured conversations and aimed to delve deeply into the needs, strengths, and opportunities for the future for children with special health care 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 data analysts for main categories and sub-themes. 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. Frequency and intensity of discussions on a specific topic were key indicators used for extracting main themes. Selected paraphrased quotes—without personal identifying information—are presented in the narrative of this report to further illustrate points within topic areas.

### *Community Survey Specifically Focused on Children with Special Health Care Needs*

A family/caregiver survey was adapted from a similar survey conducted for the CSH CHNA in 2019. The survey was administered by HRiA over a four-week period from mid-June to mid-July 2022. The survey focused on: accessibility of services and programs for children with special health care needs and their families: challenges accessing healthcare; usefulness of different services and programs; needed services and programs; telehealth utilization; and the impact of COVID-19. The survey solicited feedback from parents/caregivers of children, youth, and young adults with special health care needs as well as other family members and those who work with these children and youth. An abbreviated version of the survey was developed for young adults with special health care needs. The survey was administered online in English and Spanish.

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 included 996 respondents: 906 parents/caregivers; 71 others who engage with children with special health care needs; and 19 young adults with special health care needs. Appendix E provides a table with demographic composition of survey respondents. In this report, quantitative data for responses from parents and caregivers and other respondents are presented in charts. Data are also presented for different characteristics, including race/ethnicity, insurance status, and age of children. Data specifically from young adult survey respondents are discussed rather than visualized due to low response rate. Throughout this report, those who participated in the survey are referred to as “respondents” (whereas focus group members and interviewees 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. 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, there are several limitations that 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/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., race/ethnicity) 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.

With many organizations and residents focused on the pandemic and its effects, community engagement and timely response to data collection requests were challenging. Additionally, with its online administration method, the community survey used a convenience sample. Since a convenience sample is a type of non-probability sampling, there is potential selection bias in who participated or was asked to participate in the survey. Due to this potential bias, results cannot necessarily be generalized to the larger population. 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. Due to COVID-19, focus groups and interviews were also conducted virtually, and therefore, while both video conference and telephone options were offered, some residents who lack reliable access to the internet and/or cell phones may have experienced difficulty participating. This report should be considered a snapshot of an unprecedented time, and the findings in this report can be built upon through future data collection efforts.

# Population Characteristics

**Population Overview**

According to the 2016-2020 American Community Survey (U.S. Census), the total population of New Jersey is slightly under 9 million (Table 1). While Children's Specialized Hospital (CSH) serves children and families throughout New Jersey, its sites are located in 10 counties. The total population of the counties in which CSH facilities are located range in size from 264,650 (Atlantic County) to 825,015 (Middlesex County).

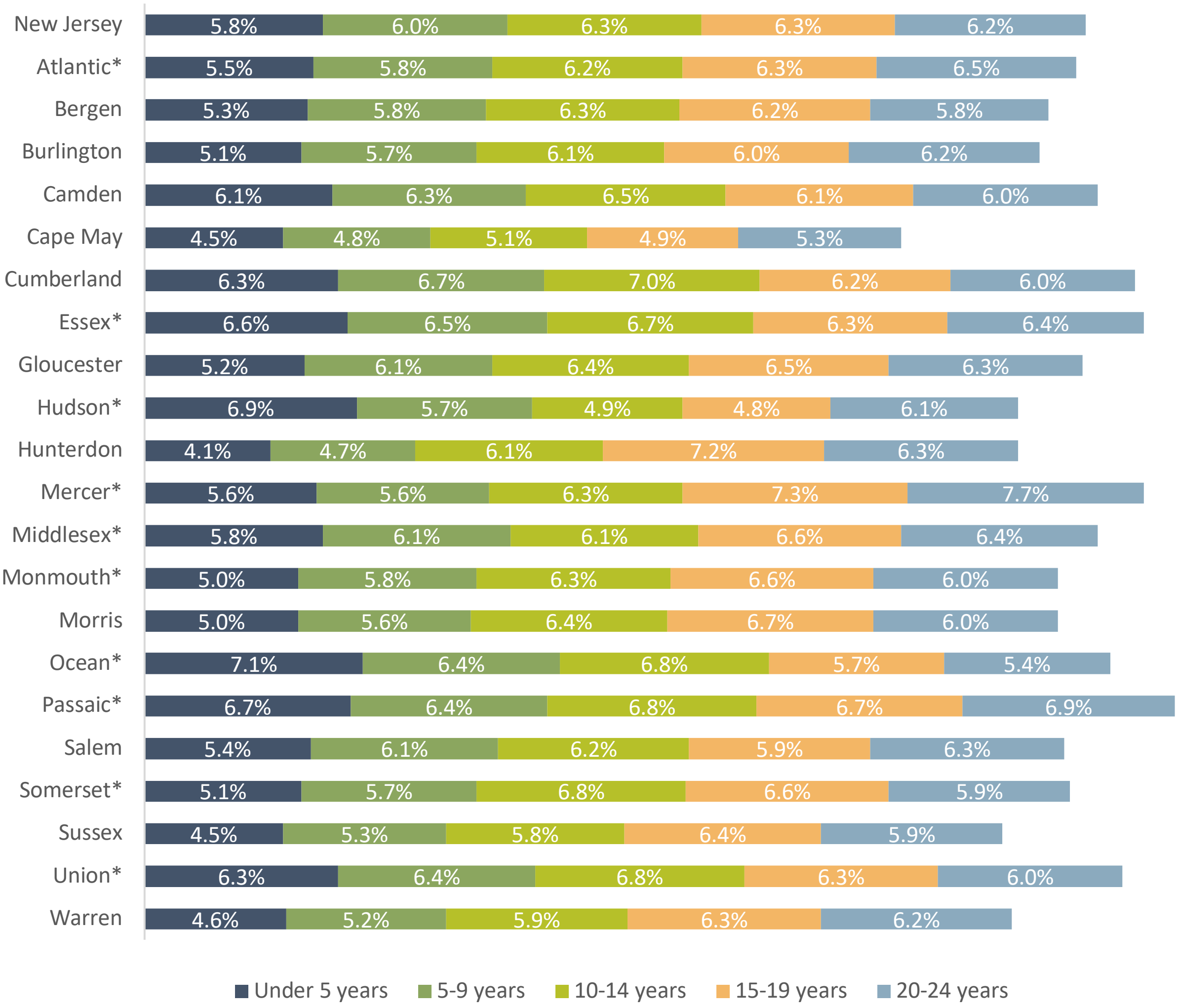
**Table 1: Total Population, by State and County, 2016-2020**

| | 2020 |
|---|---|
| New Jersey | 8,885,418 |
| Atlantic | 264,650 |
| Bergen | 931,275 |
| Burlington | 446,301 |
| Camden | 506,721 |
| Cape May | 92,701 |
| Cumberland | 150,085 |
| Essex | 798,698 |
| Gloucester | 291,745 |
| Hudson | 671,923 |
| Hunterdon | 125,063 |
| Mercer | 368,085 |
| Middlesex | 825,015 |
| Monmouth | 620,821 |
| Morris | 492,715 |
| Ocean | 602,018 |
| Passaic | 502,763 |
| Salem | 62,754 |
| Somerset | 330,151 |
| Sussex | 140,996 |
| Union | 555,208 |
| Warren | 105,730 |

DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

Approximately 30% of New Jersey's population is under age 24 (Figure 3). The proportion of residents under age 24 in counties with CSH locations ranges from 28.4% in Hudson to 33.5% in Passaic. Among counties with CSH locations, Essex, Ocean, Passaic, and Union Counties have the highest proportion of residents under age 5 while Atlantic, Essex, Mercer, Middlesex, and Passaic Counties have the highest proportion of residents between the ages of 20-24. Essex, Passaic, and Union have the highest proportion of school-age children.

**Figure 3: Age Distribution Under 24 Years, by State and County, 2016-2020**

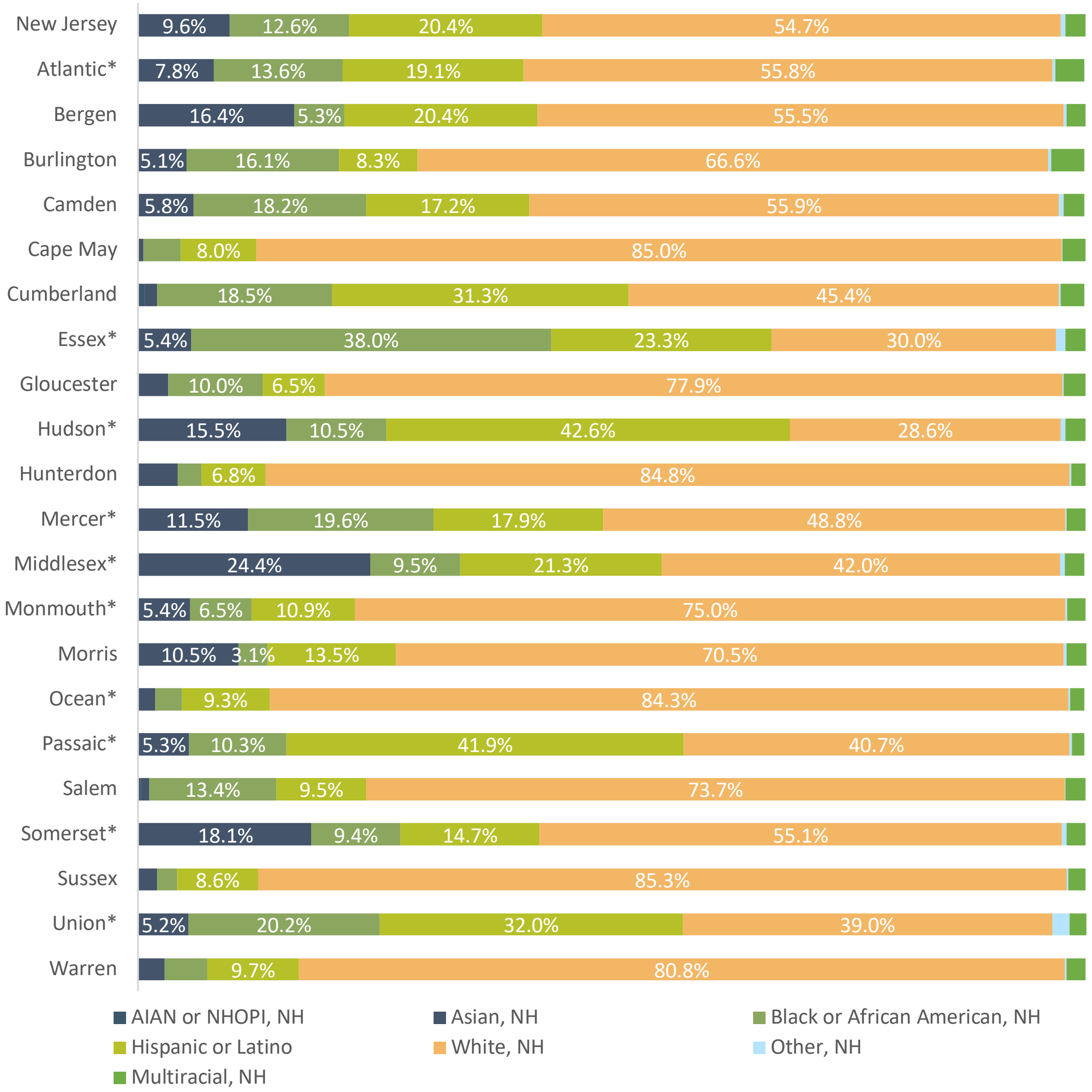


DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

## Racial, Ethnic, and Language Diversity

Figure 4 shows 2016-2020 American Community Survey data about the racial and ethnic distribution of New Jersey as a whole and by county. A majority of New Jersey residents self-identify as non-Hispanic White (54.7%), followed by residents who self-identify as Hispanic (20.4%) and non-Hispanic Black (12.6%). 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, Essex County has the highest percentage of residents who self-identify as non-Hispanic Black (38.0%); Hudson County has the highest percentage of residents who self-identify as Hispanic/Latino (42.6%); and Middlesex County has the highest percentage of non-Hispanic Asian residents (24.4%). Ocean County has the highest percentage of residents who self-identify as non-Hispanic White (84.3%).

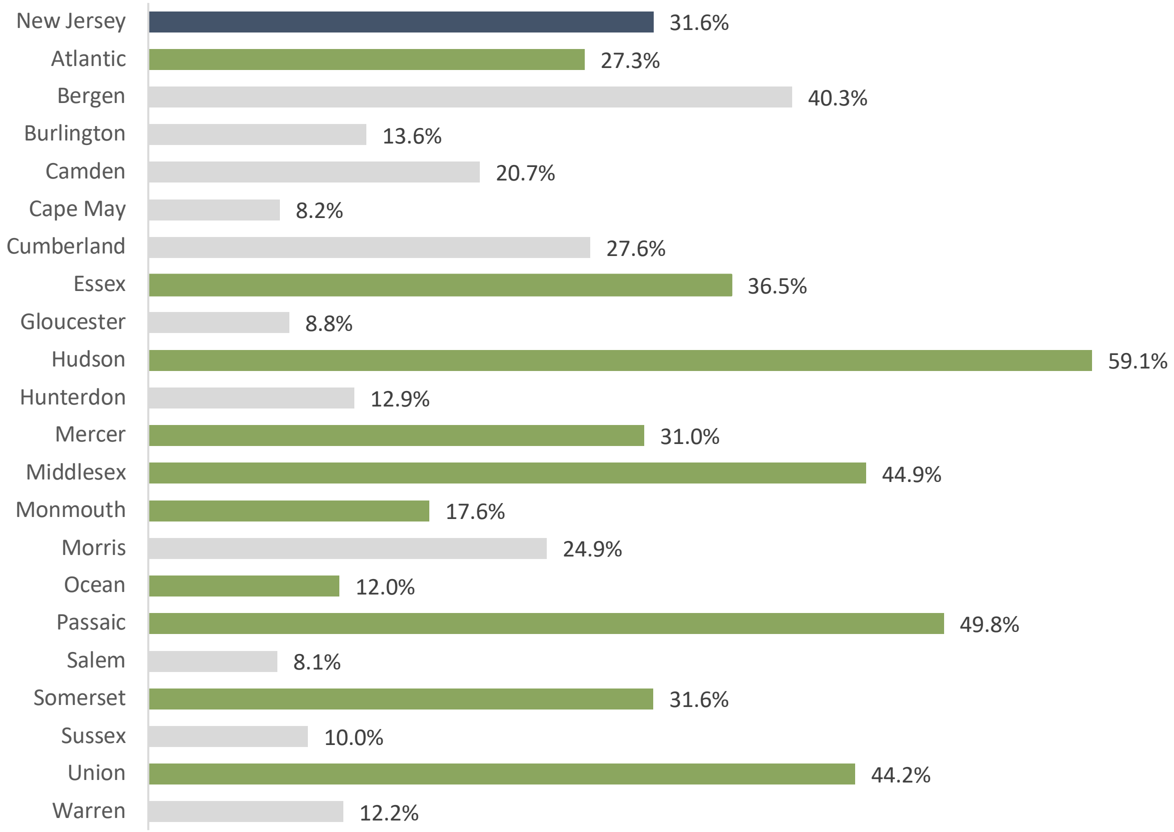
**Figure 4: Racial/Ethnic Composition, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020
NOTE: AIAN stands for American Indian and Alaska Native; NHOPI stands for Native Hawaiian and Other Pacific Islander
NOTE: Data labels under 5.0% are omitted from the graphic.

As shown in Figure 5, 31.6% of New Jersey's residents speak a language other than English at home. Among the ten counties in which CSH facilities are located, the proportion of the population speaking a language other than English at home ranges from 27.3% in Atlantic County to 59.1% in Hudson County. In five (Essex, Hudson, Middlesex, Passaic, and Union) of the ten counties, the proportion of the population speaking 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, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

About 16% 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, Passaic and Union. 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). When speaking about barriers to accessing healthcare and other services for special needs children, several interviewees and focus group members mentioned language barriers, noting that non-English speaking families face challenges accessing information about existing services and, at times, difficulty communicating with service and healthcare providers. Undocumented immigrants, they noted, face additional challenges including lack of eligibility for some services and fear of interacting with institutions.

**Table 2: Top 5 Languages Spoken at Home, by State and County, 2016-2020**

| | Spanish | Other Indo-European languages | Russian, Polish, or other Slavic languages | Other Asian and Pacific Island languages | Chinese (incl. Mandarin, Cantonese) |
|---|---|---|---|---|---|
| New Jersey | 16.4% | 5.4% | 1.7% | 1.5% | 1.4% |
| Atlantic | 16.0% | 4.4% | 0.9% | 0.5% | 1.2% |
| Bergen | 15.7% | 5.8% | 4.0% | 2.1% | 1.9% |
| Burlington | 4.7% | 2.9% | 0.8% | 1.6% | 0.5% |
| Camden | 12.5% | 2.4% | 0.6% | 0.8% | 1.0% |
| Cape May | 5.3% | 0.8% | 0.7% | 0.1% | 0.1% |
| Cumberland | 24.3% | 1.0% | 0.8% | 0.2% | 0.1% |
| Essex | 19.4% | 5.4% | 1.0% | 0.6% | 1.2% |
| Gloucester | 4.1% | 1.4% | 0.3% | 0.4% | 0.5% |
| Hudson | 37.1% | 8.3% | 1.5% | 1.7% | 2.4% |
| Hunterdon | 5.0% | 2.8% | 1.1% | 0.7% | 0.7% |
| Mercer | 14.9% | 4.9% | 2.0% | 2.3% | 2.2% |
| Middlesex | 17.0% | 13.1% | 2.1% | 4.6% | 2.6% |
| Monmouth | 7.1% | 4.0% | 1.5% | 0.7% | 1.3% |
| Morris | 10.9% | 5.6% | 1.7% | 1.9% | 2.1% |
| Ocean | 5.6% | 1.9% | 0.9% | 0.2% | 0.3% |
| Passaic | 36.3% | 5.0% | 2.3% | 1.2% | 0.4% |
| Salem | 5.6% | 1.4% | 0.2% | 0.0% | 0.0% |
| Somerset | 11.4% | 7.2% | 1.7% | 3.0% | 3.9% |
| Sussex | 4.8% | 1.4% | 1.4% | 0.3% | 0.2% |
| Union | 28.3% | 6.2% | 1.9% | 0.5% | 0.9% |
| Warren | 5.7% | 1.9% | 1.2% | 0.4% | 0.2% |

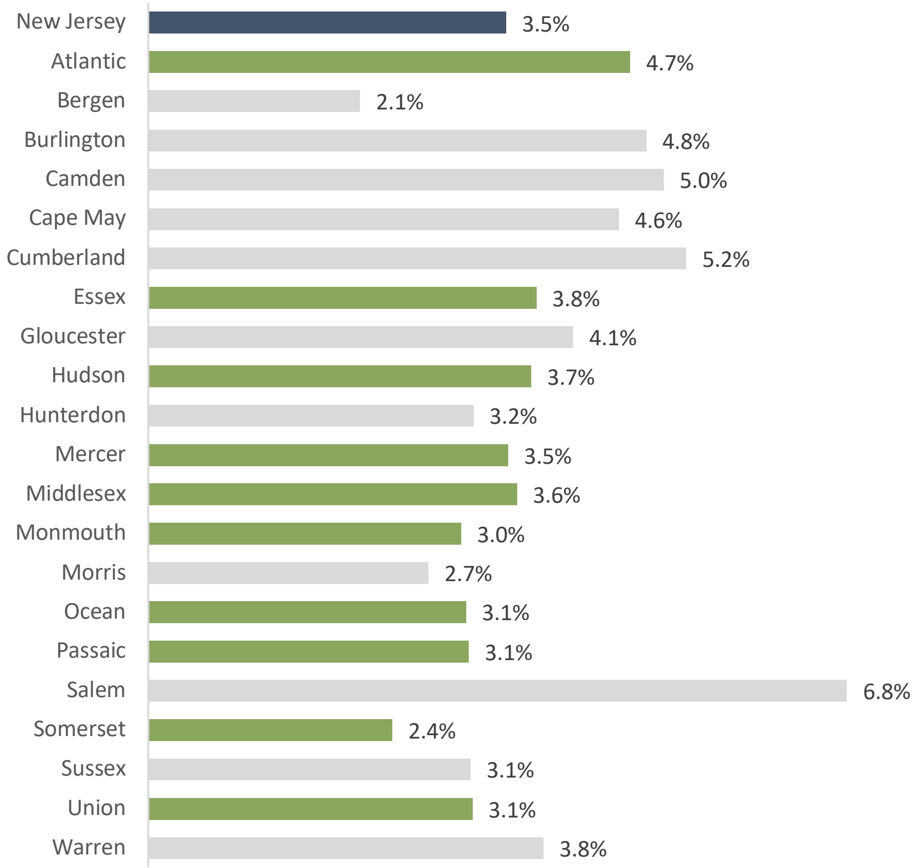
DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

### Population of Children with Special Health Care Needs in New Jersey

CSH provides inpatient and outpatient care for children with special health care needs throughout New Jersey. This section shares available secondary data about children and youth with special health care 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 2016-2020 American Community Survey, 3.5% 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). These data are available at a county level and indicate that the proportion of children and youth with disabilities in counties with CSH locations ranges from 2.4% in Somerset to 4.7% in Atlantic.

**Figure 6: Percent Population Under 18 Years with Disability, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

The National Survey of Children's Health (NSCH) collects information specifically about children and youth with special health care needs; however, these data are only available at the national and state levels. NCSH defines Children and Youth with Special Health Care Needs (CYSHCN) as "children under age 18 who are at increased risk of 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."[9] According to this survey, in 2019-2020, 19.4% of children under age 18 nationally and 17.8% of children under age 18 in New Jersey met this definition of having special health care needs.

Data from the NSCH about specific diagnoses related to special needs are presented in Figure 7. These data indicate that the proportions of children ages 3-17 with a learning disability (8.3%), a speech or language disorder (6.0%), and Autism or Autism Spectrum Disorder (ASD) (3.4%) are higher in New Jersey than nationwide (7.1%, 5.8%, and 2.9%, respectively). The proportions of children with reported anxiety problems, ADD or ADHD, behavioral or conduct problems, depression, and frequent or severe headaches are higher in the US than in the state.

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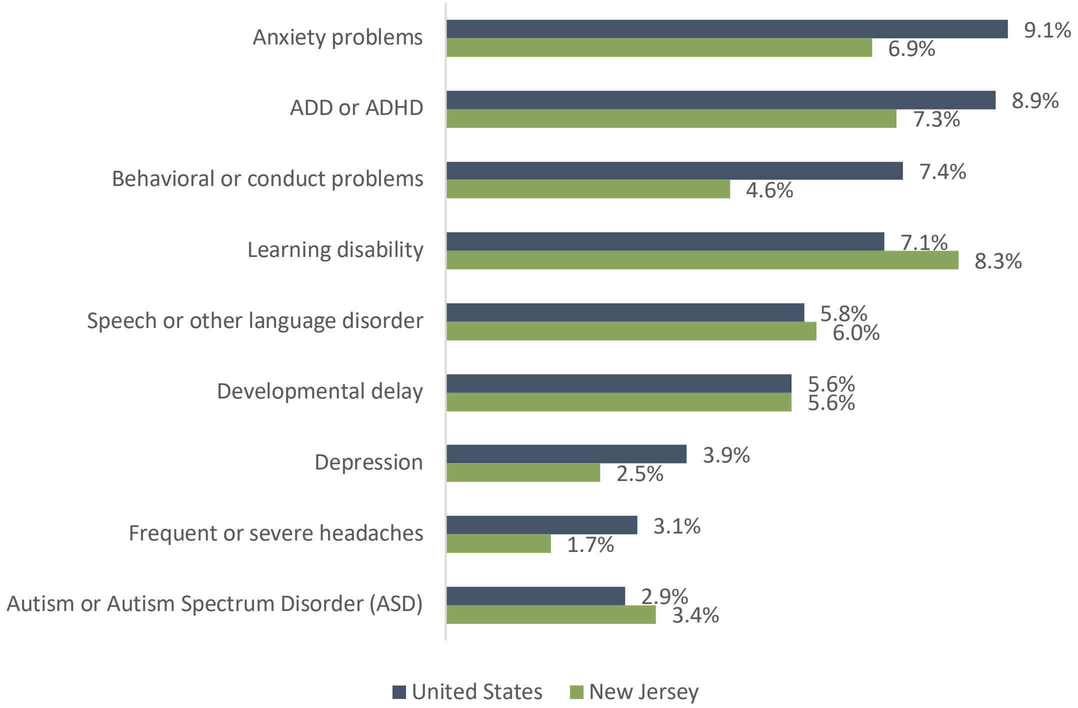
[9] https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nhsc-data-brief-children-youth-special-health-care-needs.pdf

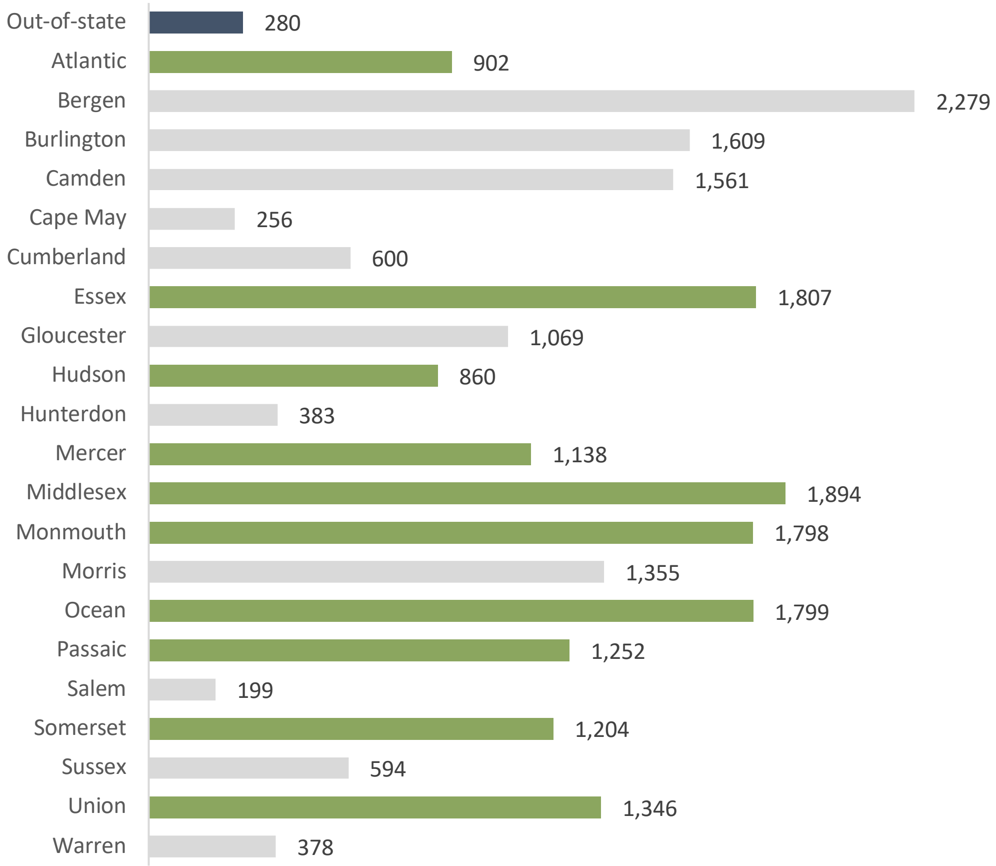
**Figure 7: Percent Children Aged 3-17 Years with Current or Lifelong Condition, by United States and New Jersey, 2019-2020**



DATA SOURCE: 2019-2020 National Survey of Children's Health

Recent data from the New Jersey Division of Developmental Disability indicate that as of the end of 2021, 24,563 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 14,000 individuals ages 10 and older were receiving services from the Division in the ten counties where CSH has sites.

**Figure 8: Individuals Receiving Services from NJ Division of Developmental Disabilities, 2021**

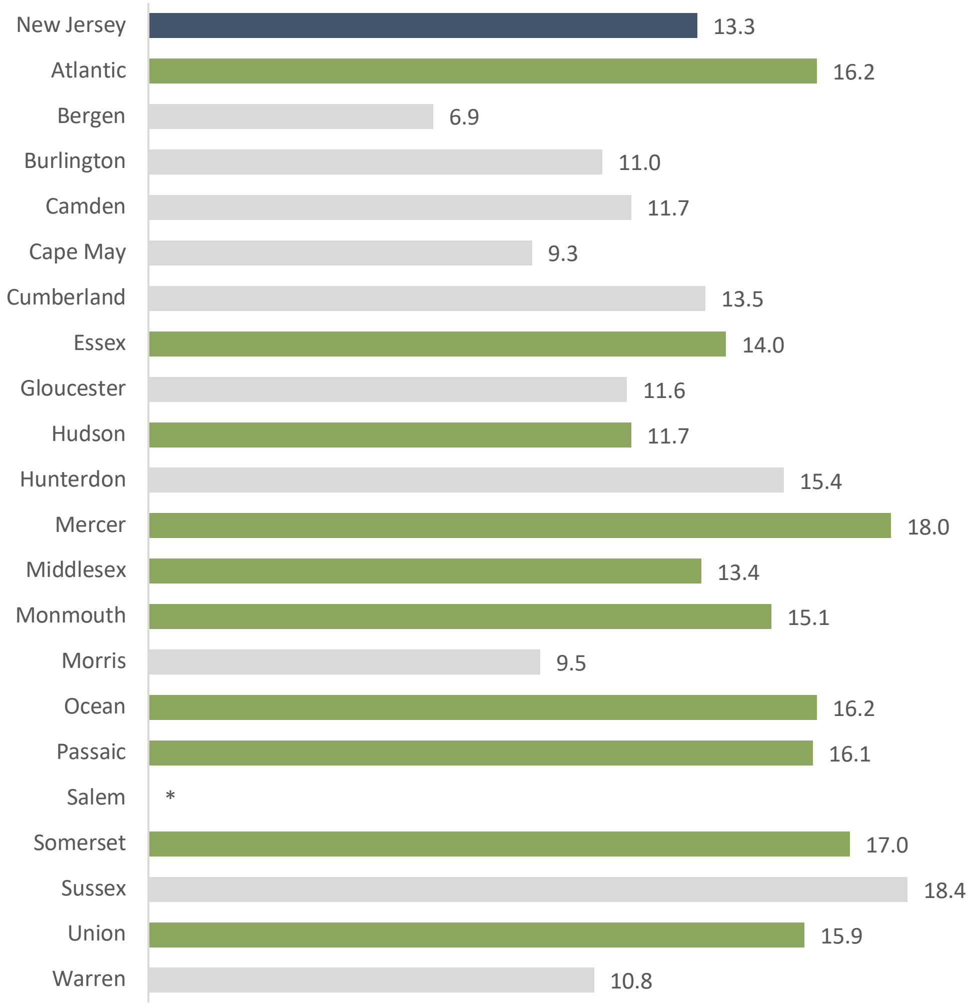


DATA SOURCE: New Jersey Division of Developmental Disability, as of 12/15/21

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.

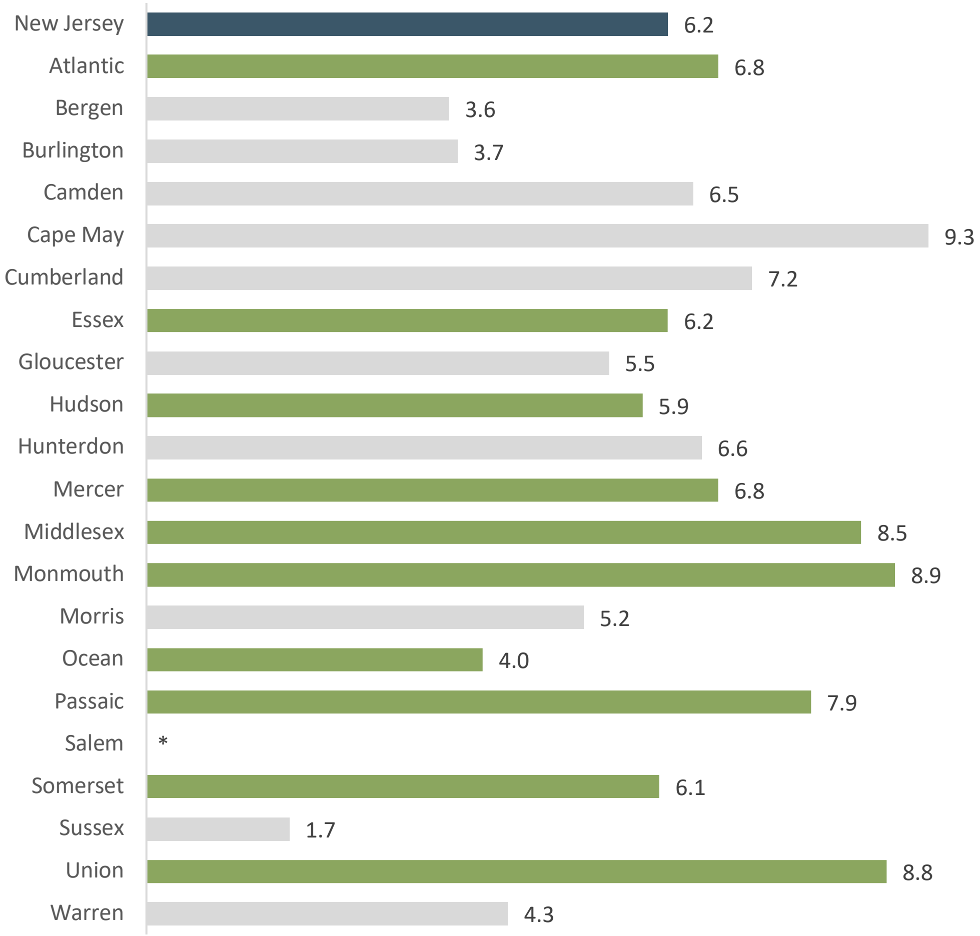
Data from the Birth Defects Registry of New Jersey for the period 2013-2017 shows 13.3 cases of chromosomal abnormalities per 10,000 births statewide (Figure 9). Of the ten counties in which CSH facilities are located, all except Hudson had a higher prevalence of chromosomal birth defects than New Jersey overall. The prevalence of Central Nervous System (CNS) birth defects was higher in five CSH Counties (Atlantic, Mercer, Middlesex, Passaic, and Union) as compared to statewide prevalence (6.2 per 10,000 births) (Figure 10).

**Figure 9: Prevalence of Chromosomal Birth Defects per 10,000 Births, by State and County, 2013-2017**



DATA SOURCE: NJ Birth Defects Registry, New Jersey Department of Health County Profiles, 2013-2017
* Data unreliable due to small number of cases.

**Figure 10: Prevalence of CNS Birth Defects per 10,000 Births, by State and County, 2013-2017**



DATA SOURCE: NJ Birth Defects Registry, New Jersey Department of Health County Profiles, 2013-2017
* Data unreliable due to small number of cases.

## 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 promote physical activity and resident engagement, better access to affordable healthy foods), and provide income and benefits to access health care. In contrast, unemployment, underemployment, and job instability make it difficult to afford housing, goods and services that are linked with health, and health care, and also contribute to stressful life circumstances that affect multiple aspects of health.

### Community Strengths and Assets

Understanding the resources and services available in a community—as well as their distribution—helps to elucidate the assets that can be drawn upon to address community health, as well as any gaps that might exist. For the CSH population, these assets are diverse and span across the state.

Interviewees and focus group participants stated that New Jersey has many resources to support children with special health care needs and their families. One interviewee shared, "*It's great to be looked at as one of those states that have it when it comes to these type of services compared to other states*." There are numerous healthcare services for children with special healthcare needs. In addition to CSH, Children's Hospital of Philadelphia, and Weisman Children's Rehabilitation Hospital serve families in New Jersey. Community survey respondents shared that in addition to these hospitals, their children have received services from St. Joseph's Hospital, the Bristol-Myers Squibb Children's Hospital at Robert Wood Johnson University Hospital, and Neumours Children's Health, among others.

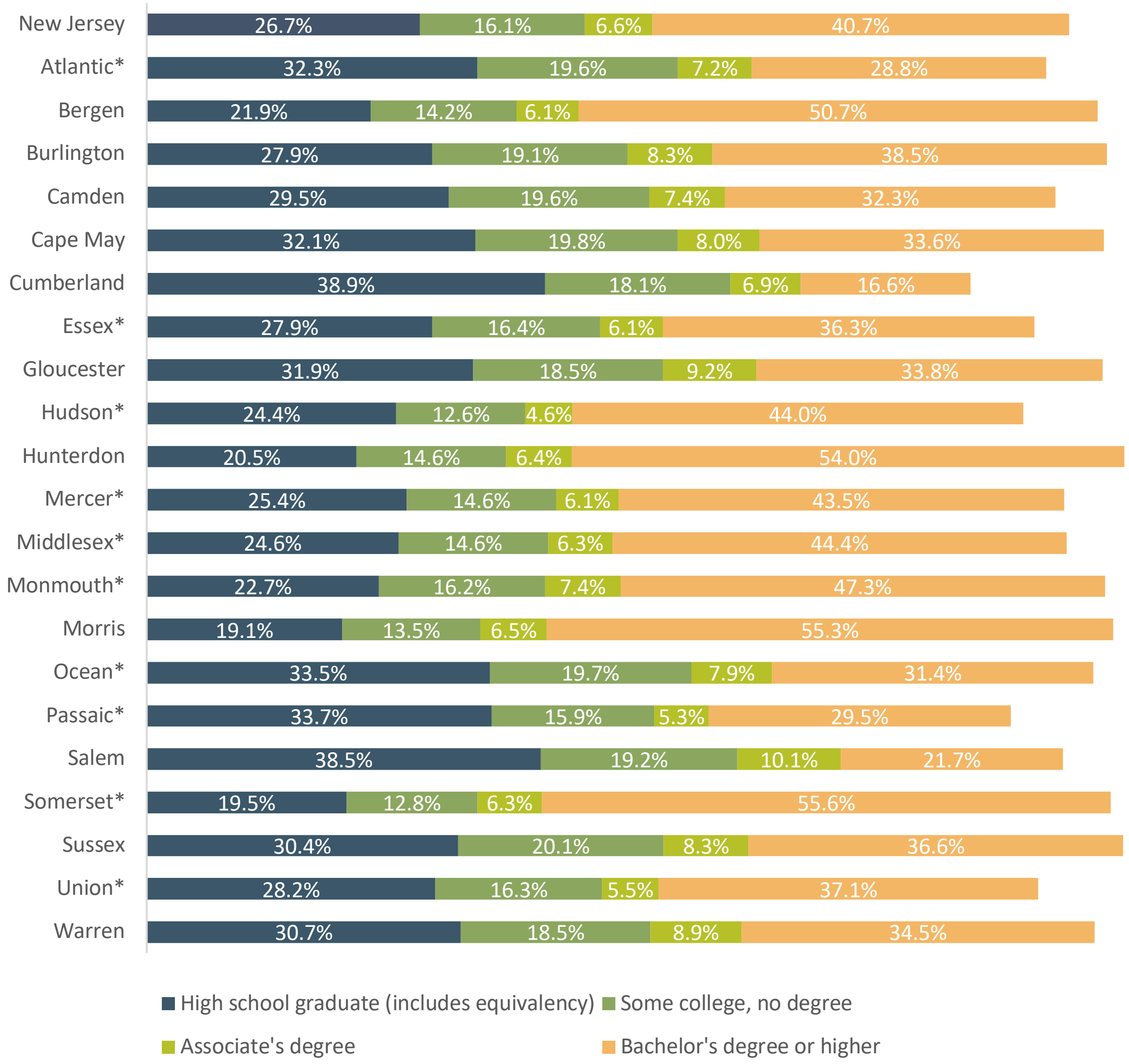
Participants also shared that the state has numerous advocacy and education organizations that support families with special needs children including the SPAN Parent Advocacy Network, the New Jersey Council on Developmental Disabilities, Arc of New Jersey, Autism New Jersey, Mom2Mom, Legal Services of New Jersey, and the Boggs Center on Developmental Disabilities at Rutgers, among others. Parents also shared that they received support and were connected to services through Perform Care, New Jersey's Children's System of Care Administrator.

The state also has programs for children and youth with special health care needs. In addition to programs offered by CSH, young people participate in programs offered at schools, Special Olympics, and other sports programs such as Pop Warner. Other resources mentioned included local libraries, community recreation programs, Boy Scouts, Embrace Kids Foundation, and Disability Allies, which builds social connections between young adults with and without intellectual development disabilities. Young people with special health care needs participating in the focus group reported that they appreciated these programs because they provided an opportunity to see and make friends, visit new places, and have new experiences.

### Education

As shown in Figure 11, 40.7% 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.

**Figure 11: Educational Attainment Among Adults Aged 25+, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

Special education data from the NJ Department of Education show that in 2019, 231,842 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 (13.2%) compared to the U.S. overall (9.7%).[10] Almost half of students (46.3%) ages 3-21 receiving special education services in New Jersey in 2020 were White, 66% were male, and 96% were non-English learners (Figure 12). Among New Jersey students ages 3-21 with special needs, about 30% had a specific learning disability, 21% had a speech or language impairment, and 21% had another health impairment (Figure 13). CSH data from the community screening program, indicate that of 3,116 children under age three screened between 2012

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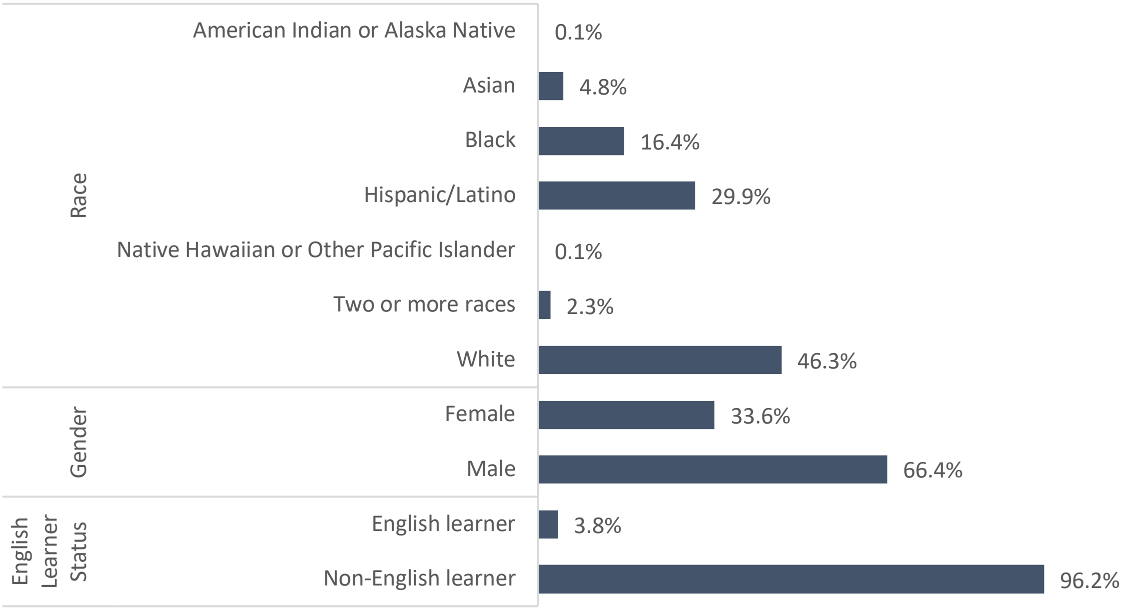
[10] DATA SOURCE: U.S. Department of Education, IDEA Section 618 Data Tables, Fall 2019 as cited by Annual Disability Statistics Compendium.

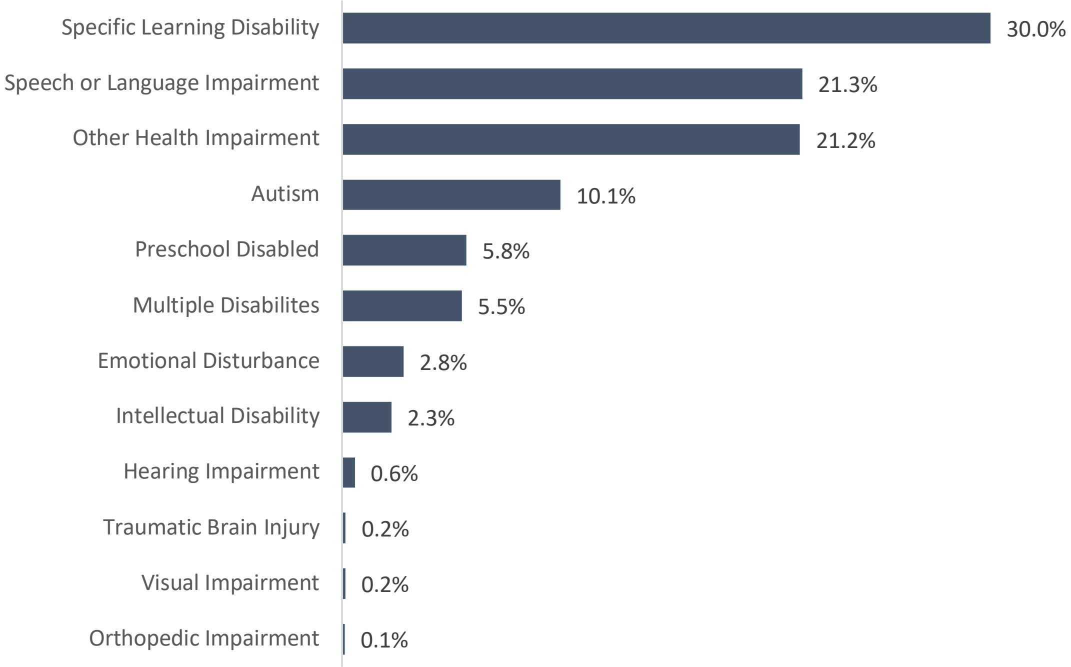
and 2022, about 54% were referred for additional evaluation; of the 79% from whom follow up data were available, 80% of parents followed through with the recommendations.

**Figure 12: Percent Special Education Students Aged 3-21, by Race/Ethnicity, Gender, English Learner Status, 2020**



DATA SOURCE: New Jersey Department of Education, 2020

**Figure 13: Percent Special Education Students Ages 3-21, by Disability, by New Jersey, 2020**



DATA SOURCE: New Jersey Department of Education, 2020

*"It depends on the school district. There are some school districts that provide really excellent support, really partner with the parents. They have specialized classes. Then there are other school districts, where it becomes a specialized placement, an out-of-district placement.*" - Key informant interviewee

Working with and navigating education systems was a frequent topic of conversation in interviews and the parent focus group. While New Jersey was generally perceived as having good services for children with special needs, participants noted that this can vary at the local level. School districts provide a variety of services in addition to education including occupational therapy (OT), physical therapy (PT), and speech, and capacity in this area was reported to be variable across districts. Living in a school district that has solid supports for children with disabilities is an overriding consideration for families, yet some are not able to afford to live in these communities.

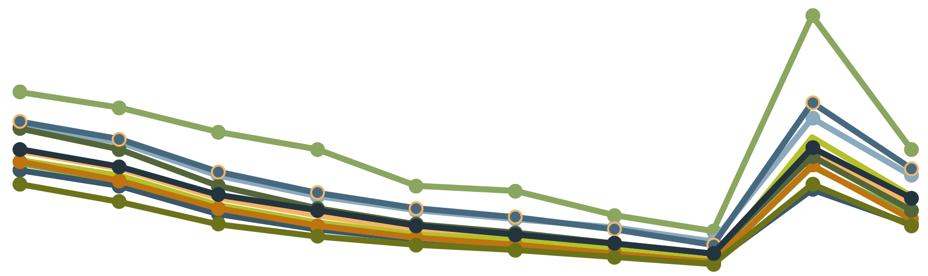
Navigating services provided by school districts can be a source of tension between school staff and parents, participants explained. As one interviewee explained, many parents want private services for their children, and these are costly and not always better than what is offered in public schools. One interviewee observed, *"A lot of contention comes up between what the parents want and what the school districts feel is appropriate to provide."* Educational placements are often the most controversial and the area in which much legal advocacy occurs. Parents, for their part, talked about the need to be active and consistent advocates for their children ensuring that they receive timely assessments, that these assessments inform development of Individual Education Plans (IEPs) and 504 plans, and that they receive services.

The impact of the COVID-19 pandemic on education was also frequently mentioned in conversations. In addition to educational loss, children with disabilities were not able to access services they received in school at home during the height of the pandemic. Parents and interviewees reported that, for many children, the lack of participation in school and services caused regression including loss of education and communication skills and substantial stress for parents. The rise in mental health concerns among children during and since the pandemic was also a theme in conversations. For some children, at home learning did not work. As one person shared, *"Many of these children have difficulty taking instruction virtually, homebound instruction becomes very difficult."* These factors substantially negatively affected student progress as an interviewee explained: *"What might have put the usual child back a year has put a child with limitations back several years."* Some parents, however, learned that having their child at home was less stressful and resulted in less acting out behavior; for example, one interviewee shared, disconnecting from social drama of school has been stabilizing for some special needs children, especially girls. Looking ahead, given challenges with the education workforce, one interviewee wondered whether there will be sufficient special education teachers and specialized coaches in the future to meet students' needs.

### Employment and Workforce

Data from the Bureau of Labor Statistics show that unemployment rates in New Jersey over the past decade had been trending downward prior to the COVID-19 pandemic, after which rates rose substantially (Figure 14). Throughout the ten years, Atlantic County had experienced higher unemployment rates than the other nine counties CSH serves and the state, while Somerset experienced the lowest rates.

**Figure 14**. **Unemployment Rate, by State and County, 2012-2021**

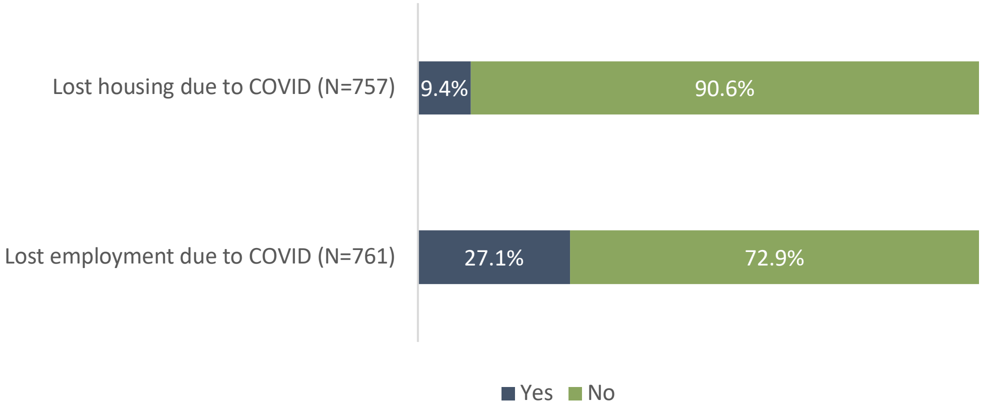


| | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 | 2021 |
|---|---|---|---|---|---|---|---|---|---|---|
| New Jersey | 9.4 | 8.4 | 6.7 | 5.7 | 4.9 | 4.5 | 4.0 | 3.4 | 9.5 | 6.3 |
| Atlantic | 12.8 | 11.9 | 10.5 | 9.5 | 7.4 | 7.1 | 5.7 | 4.8 | 17.2 | 9.5 |
| Essex | 10.8 | 9.9 | 8.0 | 6.8 | 6.0 | 5.5 | 5.0 | 4.2 | 11.3 | 8.0 |
| Hudson | 8.9 | 8.0 | 6.3 | 5.3 | 4.6 | 4.3 | 3.8 | 3.1 | 10.2 | 6.8 |
| Mercer | 8.3 | 7.4 | 5.8 | 4.9 | 4.3 | 4.0 | 3.5 | 3.0 | 7.2 | 5.2 |
| Middlesex | 8.7 | 7.7 | 6.1 | 5.1 | 4.4 | 4.0 | 3.5 | 3.0 | 8.5 | 5.7 |
| Monmouth | 8.8 | 7.7 | 6.1 | 5.1 | 4.4 | 4.0 | 3.5 | 3.0 | 8.6 | 5.5 |
| Ocean | 10.7 | 9.5 | 7.4 | 6.1 | 5.2 | 4.7 | 4.1 | 3.5 | 9.1 | 6.0 |
| Passaic | 11.1 | 10.1 | 8.2 | 7.0 | 6.1 | 5.6 | 4.9 | 4.0 | 12.2 | 8.4 |
| Somerset | 7.5 | 6.5 | 5.2 | 4.5 | 4.0 | 3.7 | 3.3 | 2.9 | 7.5 | 5.1 |
| Union | 9.5 | 8.5 | 6.9 | 6.0 | 5.1 | 4.6 | 4.1 | 3.5 | 9.6 | 6.7 |

Data from the 2022 CSH community survey indicate that about 27% of parent/caregiver respondents reported that they or a family member lost employment due to the pandemic and another 9% lost housing (Figure 15).

Consistent with themes from the parent focus group and interviews, one third or more of parent/caregiver survey respondents shared that they experienced difficulty maintaining a good mental state (51.3%), managing school at home for children (42.5%), taking care of a child with special health care needs (37.8%), financial hardship (35.9%), and maintaining good physical health (35.6%), and felt isolated and lonely (35.1%) during the pandemic (Figure 16).

**Figure 15. Percent of Community Survey Respondents Reporting that They or a Family Member have Lost Housing or Employment due to COVID, among Parents/Caregivers, 2022**



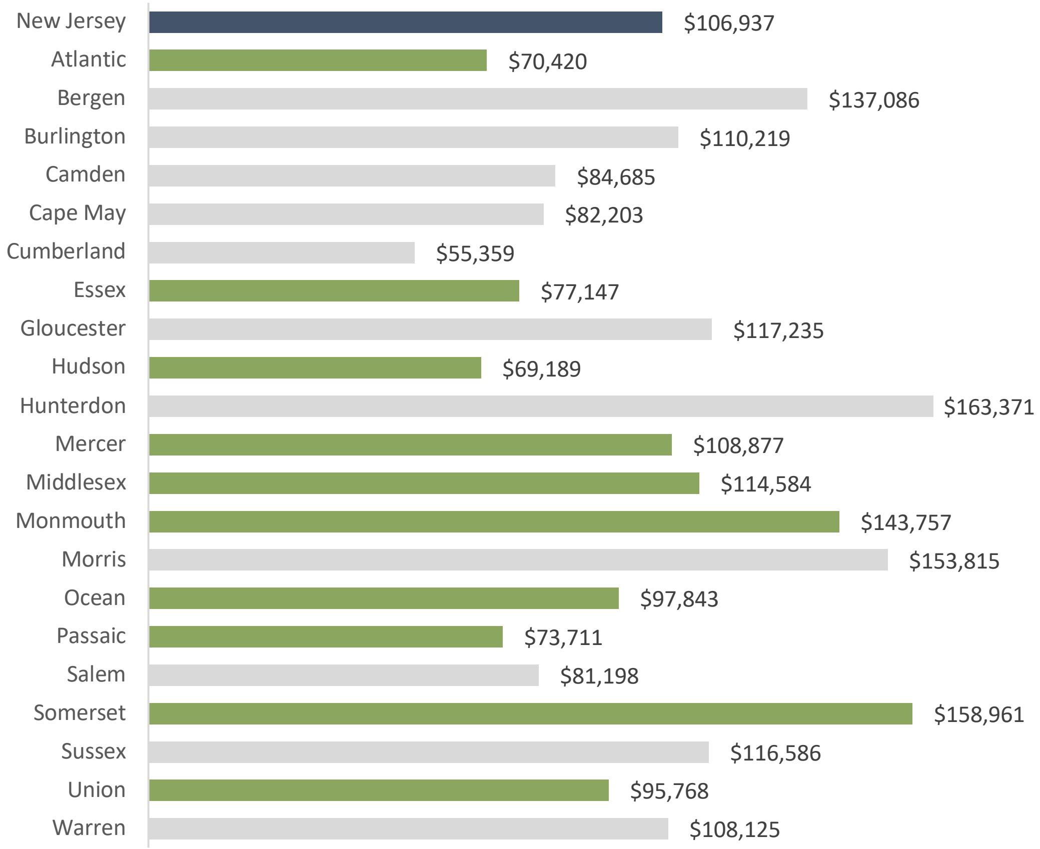
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 16. Percent of Community Survey Respondents Reporting Areas of Difficulty since COVID Pandemic, among Parents/Caregivers, n=593, 2022**

DATA SOURCE: Community Health Needs Assessment Parent/Caregiver Survey Data, Health Resources in Action, 2022

**Income and Financial Security**
Community economic indicator data show that the median household income for New Jersey is $106,937 (Figure 17). 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.

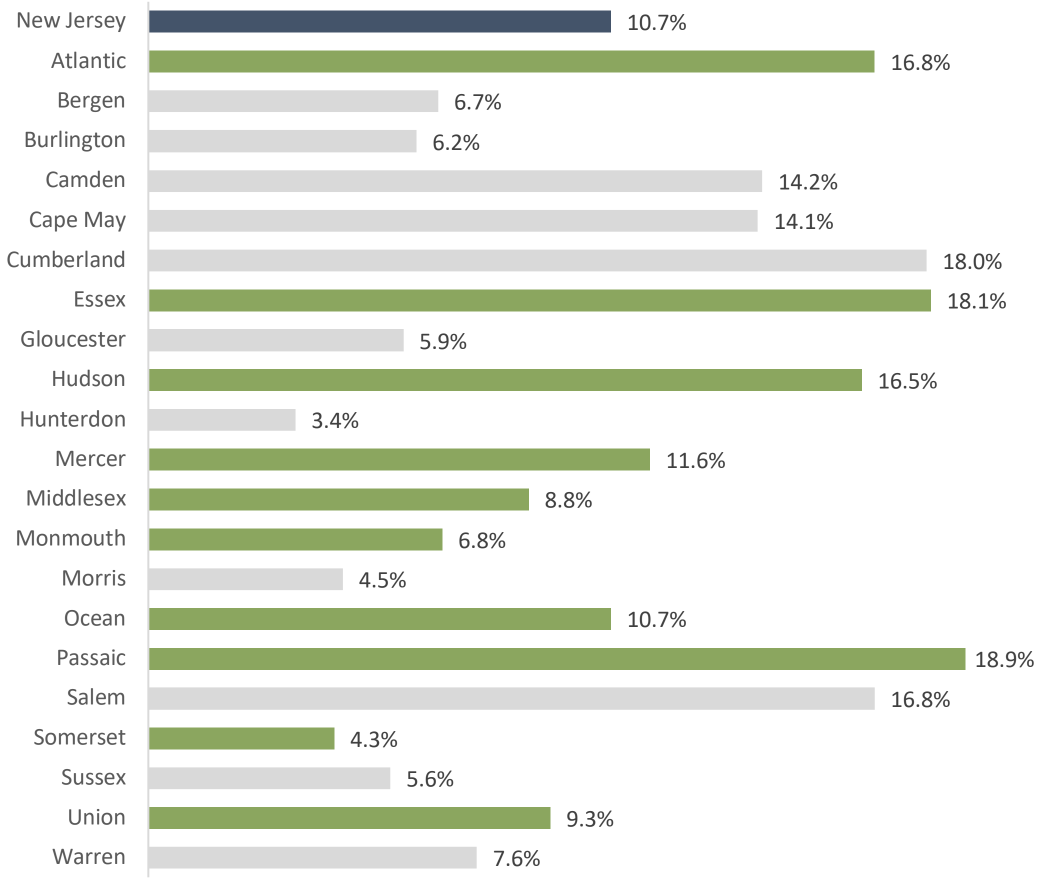
**Figure 17: Median Household Income for Households with Children Under 18, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

Slightly over 10% of families with children under age 18 in New Jersey live below the poverty line (Figure 18). In five (Atlantic, Essex, Hudson, Mercer, 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.

**Figure 18: Percent Families with Children Under Age 18 Below Poverty Level (100% FPL), by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

A recent 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.[11]

Interviewees and focus group participants stated that families with special needs children face a variety of economic challenges. Depending on a child's level of need, one parent may need to stay home for caregiving, thereby reducing family income. In discussions, a parent shared that for single-parent households, employment is challenging because it is difficult to find a daycare provider who accepts

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[11] *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

children with disabilities. Another challenge for parents is needing to take time off from work to care for their children; not all employers allow parents to do this. One interviewee working in legal services explained, "*The issue for families we hear about again and again is families not being able to miss work to go to meetings at school or health appointments for their kids. I think they miss out on so many resources*."

> *"When you look at the financial aspect, it does cost quite a bit more compared to typical children. Also, I think about the families that sort of fall in the middle – not qualifying [for benefits] to meet all their needs.* "- Focus group participant

There are also additional financial burdens, depending on a child's needs, such as transportation, equipment such as wheelchairs, a vehicle to transport this, technology for communication, and the cost of additional services and care. Families with greater resources are better able to manage these costs and associated burdens, as one interviewee stated: *"Clearly the families with more resources fare better in terms of the stresses on the family and the stresses on the caregivers than those with very little resources."*

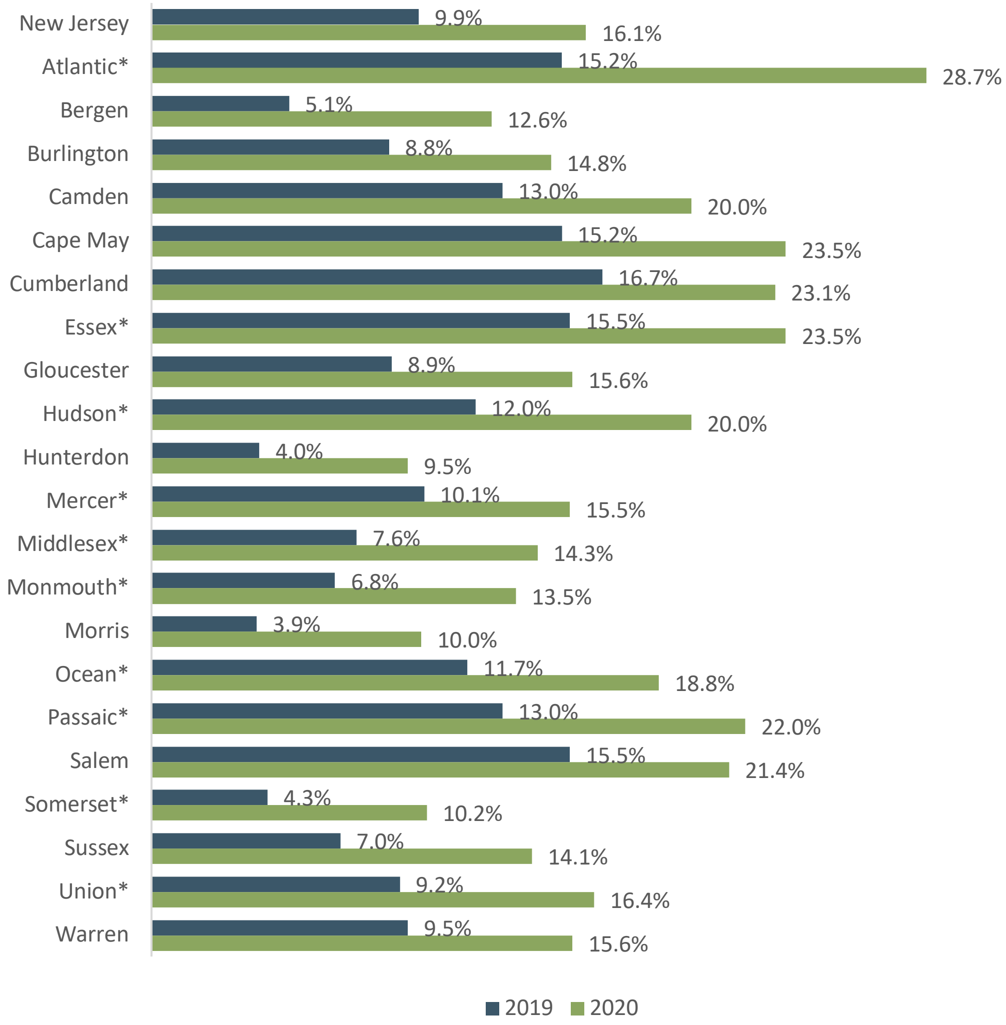
While there are supports and resources available to help families, not all qualify. Undocumented families, for example, are often unable or fearful of accessing resources for a child with special needs. Lower income families are also vulnerable, as one person shared: "*Day-to-day paying bills meeting expenses, worried about evictions, everything is exacerbated for lower income families trying to meet their basic needs to survive."* Administrative barriers can also get in the way of accessing services, interviewees reported. An interviewee providing legal services shared that many families with special needs children seek help getting social security benefits for their children and following up on denied claims for food stamps and other benefits.

**Food Access and Food Security**

While many food access barriers are related to income constraints, access may also be more challenging for residents due to geography and transportation challenges.

Figure 19 shows differences in the proportion of residents under age 18 who were food insecure in both 2019 and 2020. As evident by the substantial increase between these two years, COVID had a substantial effect on food insecurity. The proportion of children food insecure overall in New Jersey increased from 9.9% to 16.1% over these two years. The most substantial increase over these years occurred in Atlantic County, from 15.2% in 2019, to 28.7% in 2020. In 2020, five (Atlantic, Essex, Hudson, Ocean, and Passaic) of the ten counties in which CSH has locations had higher rates of child food insecurity than the state overall.

**Figure 19: Percent Under 18 Food Insecure, by State and County, 2019 and 2020**



DATA SOURCE: Feeding America, Map the Meal Gap 2021
NOTE: 2020 data are projections of food insecurity levels in response to projected changes to annual unemployment and poverty due to COVID-19.

As for many families, food insecurity is a concern among families with special needs children, particularly as food prices have risen. 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. Data from the CSH SDOH screening survey indicate that 21.4% of CSH families were identified as food insecure in the first quarter of 2022.[12] Organizations such as the New Jersey Food Bank have partnered with CSH to provide food boxes for patients' families and interviewees report that this has helped families. Yet all families who need this support may not be receiving it. One interviewee explained that stigma about needing help prevents some families with children with special needs from accessing food programs.

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[12] Data collected from 2,297 screenings, conducted January 1 through March 31, 2022.

### Housing

American Community Survey data from 2016-2020 indicate that in New Jersey, 46.2% of homeowners and 62.2% of renters spend 25% or more of their household income on housing costs (Figure 20 on the following page). In seven (Atlantic, Essex, Hudson, Middlesex, Ocean, Passaic, and Union) of the ten counties with CSH locations, a higher proportion of homeowners than the state spend 25% or more of their household income on housing costs. Similarly, in six (Atlantic, Essex, Monmouth, Ocean, Passaic, and Union) of the ten counties with CSH locations, a higher proportion of renters than the state spend 25% or more of their household income on housing costs.

Data from the ALICE report on financial hardship among people with disabilities indicates 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.[13]

Interviewees and focus group participants identified housing as a concern among families with special needs children. Like many families, parents of children with special health care needs face high housing costs, which have risen since the pandemic. Evictions have also increased according to one interviewee. For families with special needs children, accessibility is important and not always present in available housing. One interviewee stated, *"We have families carrying their children up three floors and their fear is what happens when they can no longer lift and carry their child."* Interviewees also mentioned that some families live in poor quality housing, with conditions such as lead paint and mold, that can negatively affect their children's health. Recent data from the CSH SDOH screening survey identified that 3.8% of CSH families were without steady housing and another 9.7% were concerned with losing their current housing.[14] When asked about housing issues, utility shut off (9.2%), pests (5.9%), and leaks (3.9%) were most frequently mentioned.

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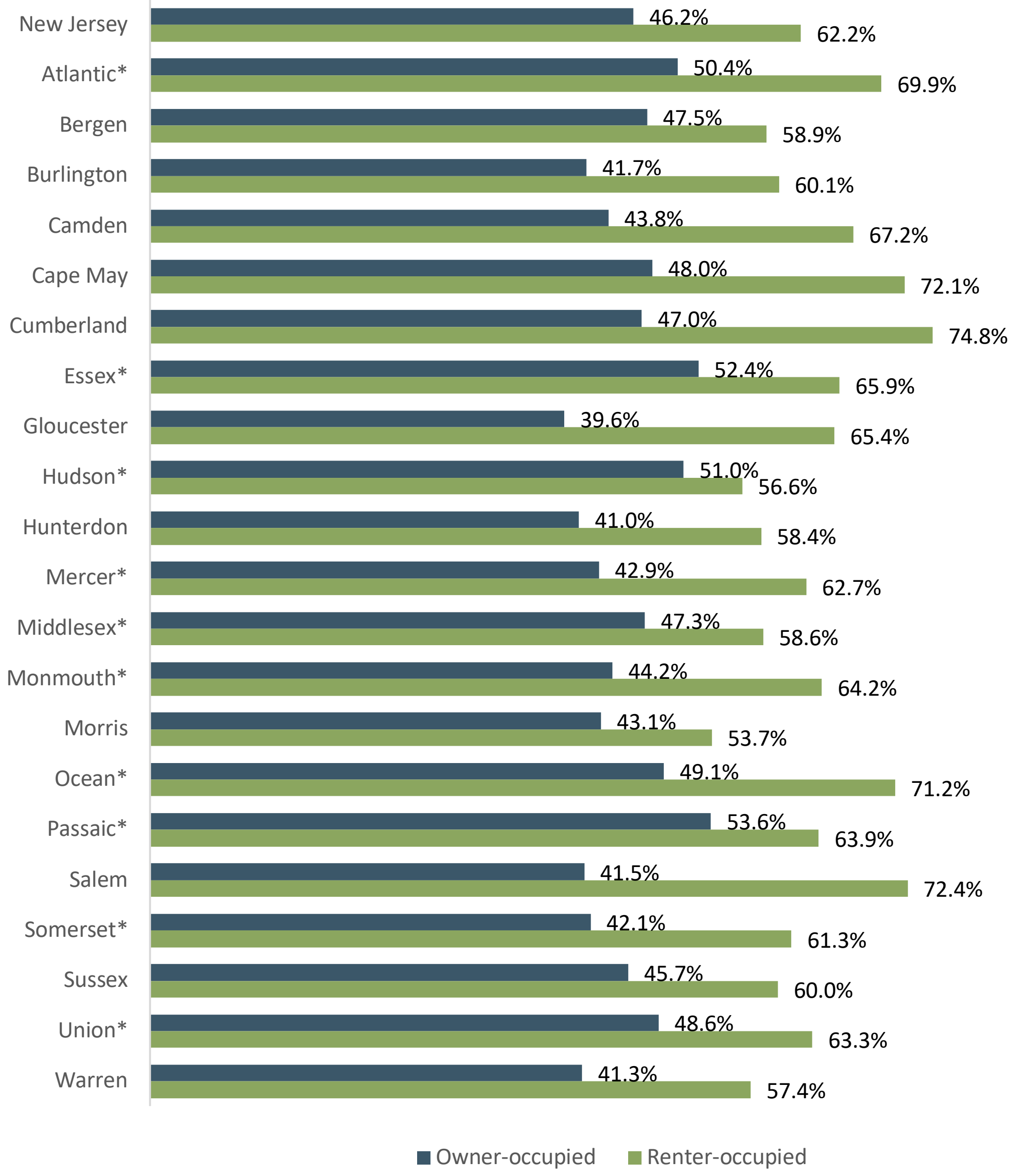
[13] *ALICE in Focus: Financial hardship among people with disabilities*. July 2022. United for ALICE. https://www.unitedforalice.org/Attachments/ALICEInFocus/ALICE-in-Focus-Disabilities-National.pdf

[14] Data collected from 2,297 screenings, conducted January 1 through March 31, 2022.

**Figure 20: Percent Households Whose Housing Costs are 25% or More of Household Income, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

**Transportation**

*"Currently, accessible transportation systems are not easy to use. You have to be ready long before you want to be picked up and have to wait a long time for them to come and get you."* – Community survey respondent

As illustrated in Figure 21, 11.2% of households in New Jersey did not have access to a vehicle according to the 2016-2020 American Community Survey. Among the ten counties with CSH locations, four (Atlantic, Essex, Hudson, and Passaic) have a higher proportion of households without access to a vehicle than the state. Notably, almost one third of Hudson County households and almost one quarter of Essex County households do not have access to a vehicle.

A few interviewees talked about challenges of transportation access for families with special needs children. One community survey respondent wrote: *"Transportation can be hard to get my child to his appointment."* They stated that it can be difficult to utilize public transportation with special needs children. Additionally, depending on the nature of the disability, some families require a specialized vehicle. While there are services to provide transportation support for children with special health care needs, including Access Link and LogistiCare, some participants and survey respondents reported that there are challenges with these services including difficulty scheduling rides, long wait times to be picked up, and sometimes no shows. Data from the CSH SDOH screening survey show that in early 2022, 8.1% of CSH families screened reported general transportation issues and 3.5% reported school transportation issues.[15]

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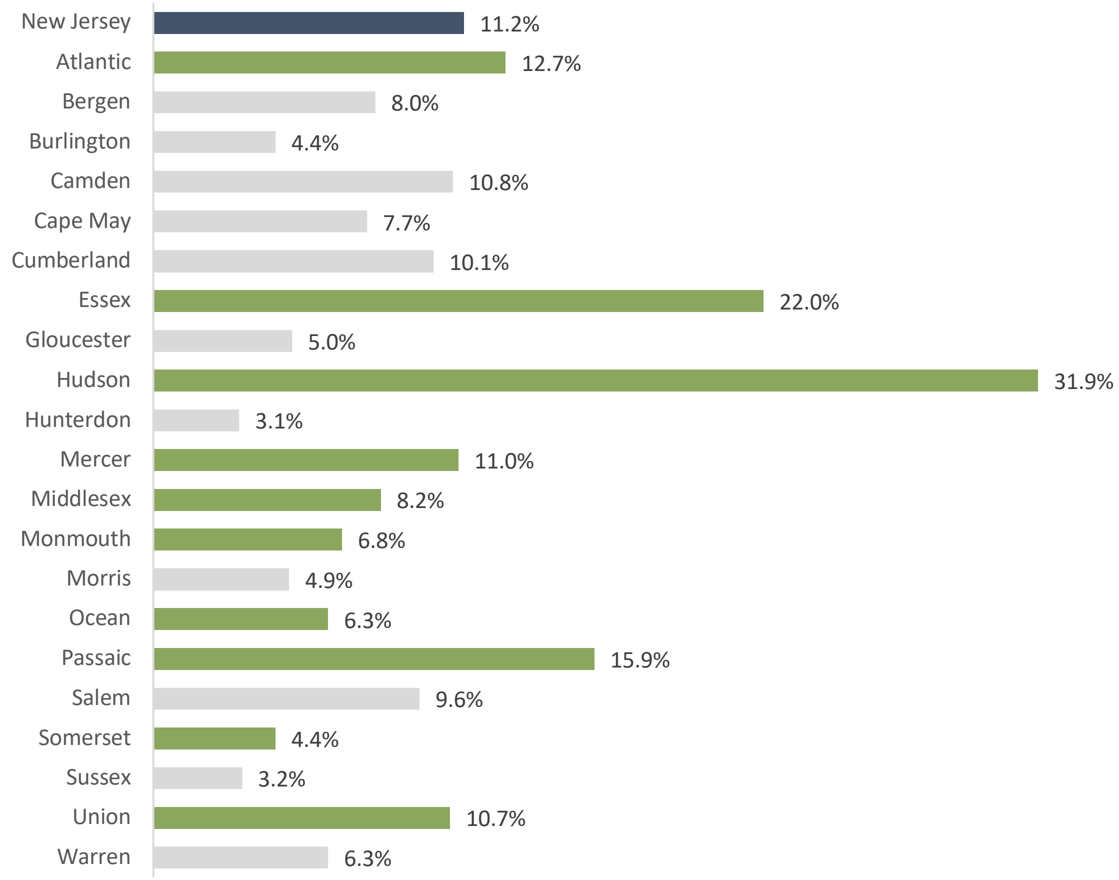
[15] Data collected from 2,297 screenings, conducted January 1 through March 31, 2022.

**Figure 21: Percent Households Without Access to a Vehicle, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

### Crime and Violence

Data from the 2019-2020 National Survey of Children's Health indicate that a smaller proportion of children with special health care needs (55.3%) experienced one or more adverse childhood experiences[16] than those without special needs (65.4%) (Figure 22).

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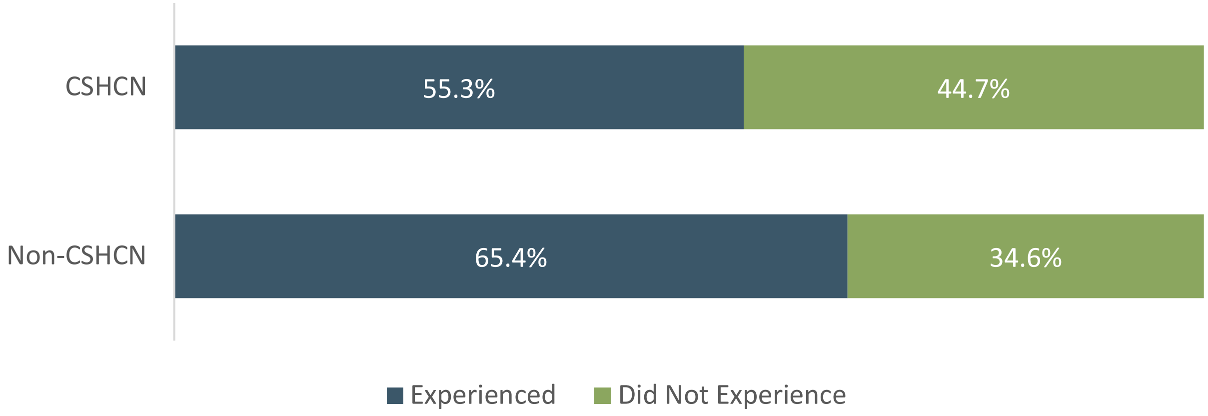
[16] Adverse childhood experiences (ACEs) in the NSCH are defined as one or more of the following: Parent/guardian divorced or separated; Parent/guardian died; Parent/guardian served time in jail; Saw or heard parents or adults slap, hit, kick, punch one another in the home; Was a victim of violence 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.

**Figure 22: Percent Children Who Experienced One or More Adverse Childhood Experiences by CSHCN Status, New Jersey, 2019-2020**



DATA SOURCE: National Survey of Children's Health, 2019-2020

### Systemic Racism and Discrimination

While challenges related to discrimination and racism were not prevalent themes in conversations with interviewees and focus group participants, a few shared that parents of children with special health care needs who do not speak English face challenges accessing services for their children and finding parent support groups and programs in which they can participate. More often, parents and caregivers shared that they were treated differently because their children had special needs. Several parent focus group members shared that they experienced disrespect from health care providers and school staff. As one parent explained, *"We saw the doctor for a cold. I felt like the pediatrician wasn't listening and there was a lot of assumptions being made about my daughter."* About 8% of community survey respondents who were parent/caregivers identified discrimination/unfriendliness of doctors and office staff and 6% identified language as barriers to accessing health care. About 14% of Hispanic parent/caregiver respondents reported language barriers and about 14% of parent/caregiver respondents who identified as being of another race or multi-racial reported discrimination/unfriendliness as a barrier.

### Technology

In New Jersey for the time period 2016-2020, approximately 93% of households had a computer and 88.1% had access to the internet (Figure 23).

Four (Essex, Ocean, Passaic, and Union) of the ten counties with CSH locations had a slightly lower proportion of households with a computer than the state overall and seven (Atlantic, Essex, Hudson, Mercer, Ocean, Passaic, and Union) of the ten had a lower proportion of households with internet access than the state. 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.[17]

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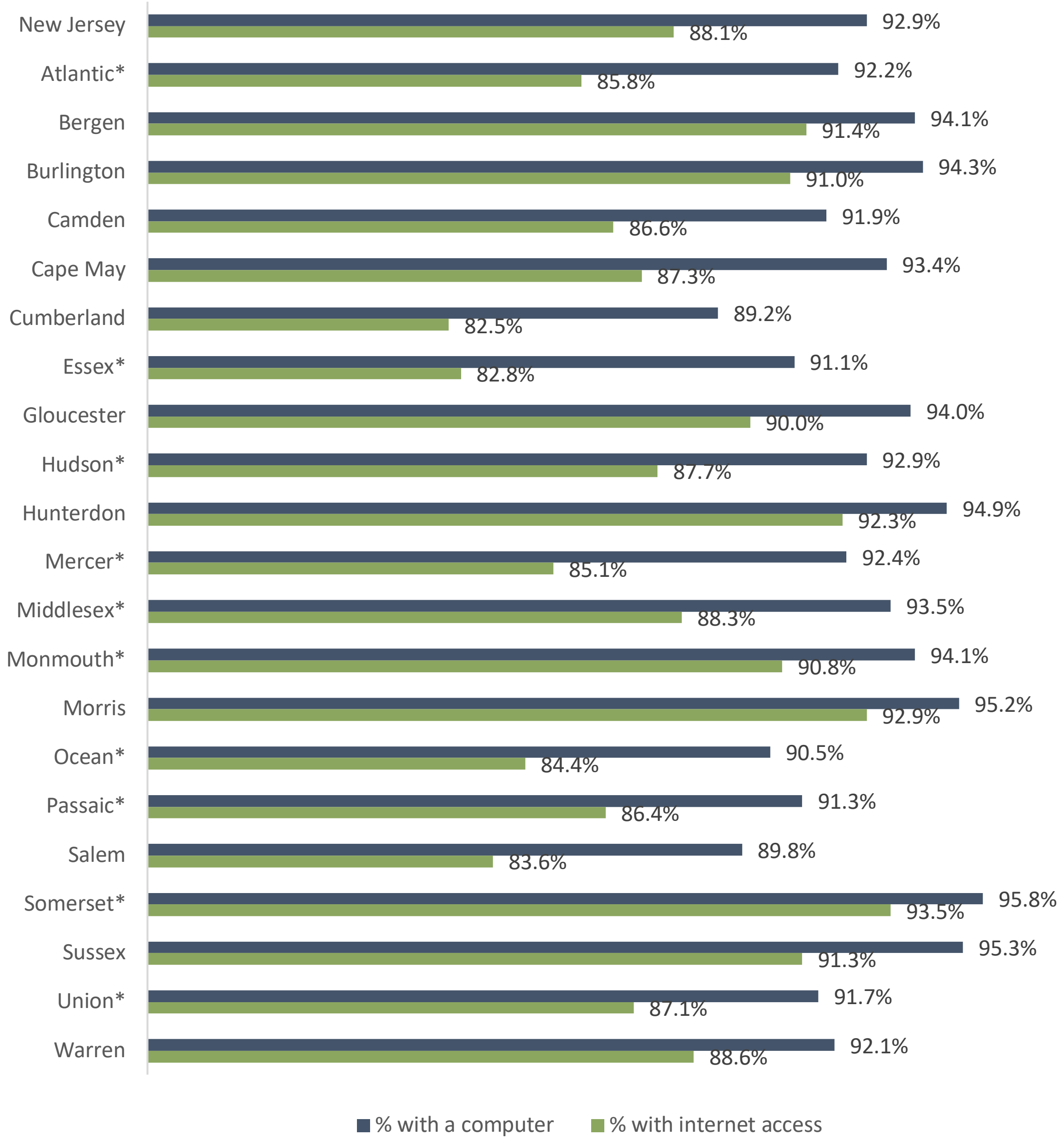
[17] *ALICE in Focus: Financial hardship among people with disabilities*. July 2022. United for ALICE. https://www.unitedforalice.org/Attachments/ALICEInFocus/ALICE-in-Focus-Disabilities-National.pdf

**Figure 23: Percent Households with a Computer and Internet Access, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

## Community Health Issues

Understanding community health issues is a critical step in the CHNA process. The disparities seen in these issues mirror the historical patterns of structural, economic, and racial inequities experienced for generations across the city and the U.S.

**Overall Child Health**

The National Survey of Children's Health (NSCH) from 2019-2020 provides a picture of overall health among children and youth with special health care needs. Data are presented for New Jersey and compared to the nation; data are not available at the county level. In 2019-2020, 91.3% of children in New Jersey were described as being in "excellent" or "very good" health, a proportion similar to the nation (Figure 24). In that same year, 17.8% of children in New Jersey had special health care needs, compared to 19.4% for the nation.

**Figure 24. Overall Child Health, by US and New Jersey, 2019-2020**

| | United States | New Jersey |
|---|---|---|
| Excellent or Very Good | 90.4% | 91.3% |
| Good | 8.0% | 7.6% |
| Fair or Poor | 1.5% | 1.1% |

DATA SOURCE: National Survey of Children's Health, 2019-2020

**Healthy Eating and Physical Activity**

Data about risk behaviors among high school youth in New Jersey come from the 2019 Youth Risk Behavior Survey (YRBS) and are presented in Table 3. Data are not available at the county level. In 2019, 11.9% of New Jersey high school students were obese while 14.7% were overweight. Slightly over 5% reported that year that they had not consumed fruit in the week prior to the survey.

**Table 3: Obesity, Overweight, and Fruit Consumption among High School Students, by New Jersey, 2019**

| | % |
|---|---|
| Percent High School Students Classified as Having Obesity | 11.9% |
| Percent High School Students Classified as Being Overweight | 14.7% |
| Percent High School Students Reporting No Fruit Consumption In Past Week | 5.5% |

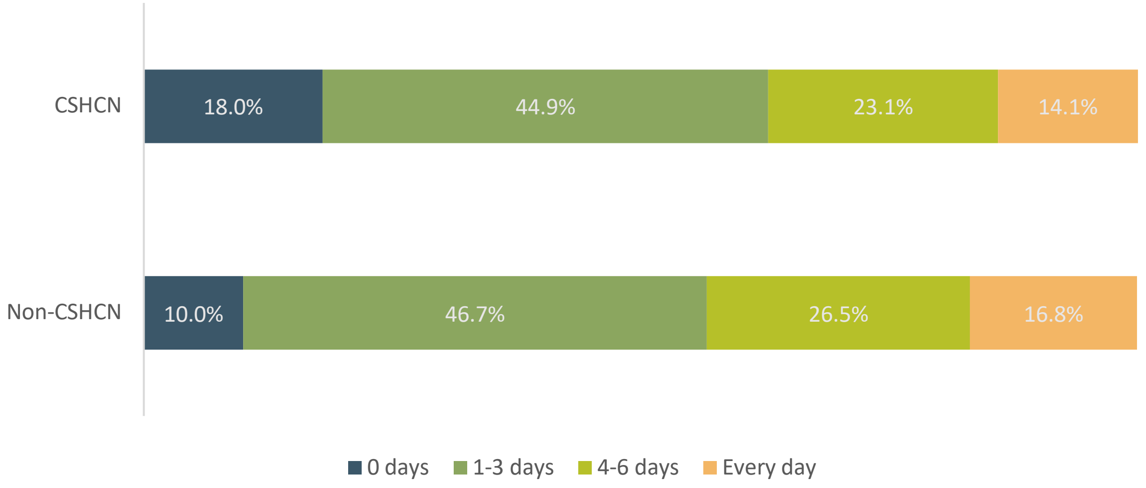
DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC 2019

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 2019-2020 National Survey of Children's Health indicate that a smaller proportion of children with special health care 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 25).

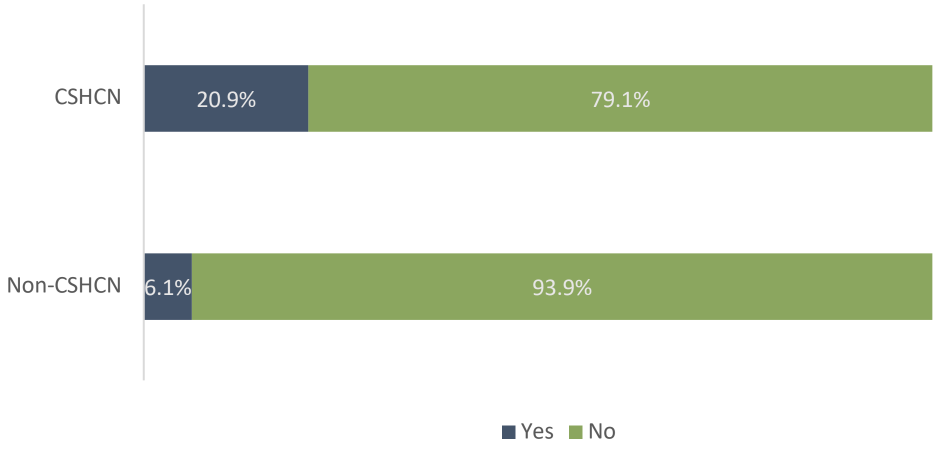
According to survey results, 20.9% of parents of children with special health care needs in New Jersey have been told by a doctor or other health care provider that their children are overweight, compared to 6.1% of other children (Figure 26).

**Figure 25: Percent Children Ages 6-17 Participating in Physical Activity During the Past Week, by Frequency, by CSHCN Status, New Jersey, 2019-2020**



DATA SOURCE: National Survey of Children's Health, 2019-2020

**Figure 26: Percent Children Ages 6-17 Who Have Identified as Overweight by a Doctor or Other Health Provider, by CSHCN Status, New Jersey, 2019-2020**



DATA SOURCE: National Survey of Children's Health, 2019-2020

## Behavioral Health: Mental Health and Substance Use

Table 4 presents data about behavioral health for New Jersey high school youth; data are not available at the county level. In 2019, 35.8% of New Jersey high school students reported feeling persistently sad or hopeless in the prior year and 14.5% reported that they had seriously considered suicide. Additionally, about 30% reported that they consume alcohol and 28% reported that they vaped.

**Table 4. Mental Health Status and Substance Use among High School Youth, by New Jersey, 2019**

| Mental Health | % |
|---|---|
| Percent High School Students Feeling Persistently Sad or Hopeless During Past Year | 35.8% |
| Percent High School Students Who Seriously Considered Suicide | 14.5% |
| Percent High School Students Who Attempted Suicide | 5.9% |
| **Substance Use** | **%** |
| Percent High School Students Who Currently Smoke Cigarettes | 3.8% |
| Percent High School Students Who Currently Use Electronic Vapor Products | 27.6% |
| Percent High School Students Who First Drank Alcohol Before Age 13 | 12.8% |
| Percent High School Students Who Currently Drink Alcohol | 30.3% |
| Percent High School Students Who Report Current Binge Drinking | 15.3% |
| Percent High School Students Who Currently Use Marijuana | 20.1% |

DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC 2019

> *"Patients with mental health needs need to see a professional in a timely manner. A child's status can significantly decline or decompensate very quickly when they are not able to get an appointment with a psychologist."* – Community survey respondent

Mental health was identified as a challenge for families with special needs children across all interviews, in the parent focus group, and among community survey respondents. As described earlier, the COVID-19 pandemic created many stresses for special needs children and youth and their families and increased demand for mental health services. One interviewee working in schools described anxiety, worry and fear of illness and death of loved ones, and exacerbation of conditions like obsessive compulsive disorder (OCD). Mental health challenges manifest in another way as well, as one interviewee explained: *"A hard thing with some of our kids is that pressure to keep the kid going and moving, and that takes a toll on mental health. Parents pushing their kids academically, you need to make friends, you need to be like everybody else, and not realizing what that's doing to the student."* As described in the Access to Services section below half of parent/caregiver survey respondents identified behavioral/mental health care as very hard or hard to access in their communities.

Finding mental health providers for children with special healthcare needs is a substantial challenge. Interviewees, parents participating in the focus group, and survey respondents reported waitlists for mental health services; some providers limit the insurance they will accept or are not taking new patients. As one community survey respondent wrote, *"There are not enough mental health services for children with special needs or ABA (Applied Behavioral Analysis) facilities. The facilities that are available are expensive and not covered by Medicaid or need to be on a waitlist."* There are even fewer supports, participants reported, for young adults who have aged out of the pediatric system and need mental health services. Insurance coverage is also an issue as insurance does not always cover psychologists, social workers, and counselors. While parents reported that there are private options for mental health, these are expensive and not accessible to all. There are additional barriers for some families, according to interviewees and focus group participants. Lower income families, for example, tend to have many other stressors and addressing mental health may not be prioritized. Culture also plays a role; in some cultures, there is substantial stigma surrounding mental health, as well as stigma relative to people who have special needs, which may lead some to be reluctant to seek out mental health services.

The quality of mental health care for children with special health care needs is also a concern, participants report. Some parents stated that they do not see the same mental health provider at each appointment, which can be particularly difficult for those children for whom consistency is critical. Diagnosis is an additional challenge, parents report: providers need to be able to distinguish between mental health issues and behaviors associated with a neural development diagnosis, and not all are adept at this. As a result, children with special needs may not receive appropriate care. One interviewee shared: *“I've seen kids get put in isolation when it's not necessary because isolating the child is gonna make the issue worse. We really just need to evaluate.”*

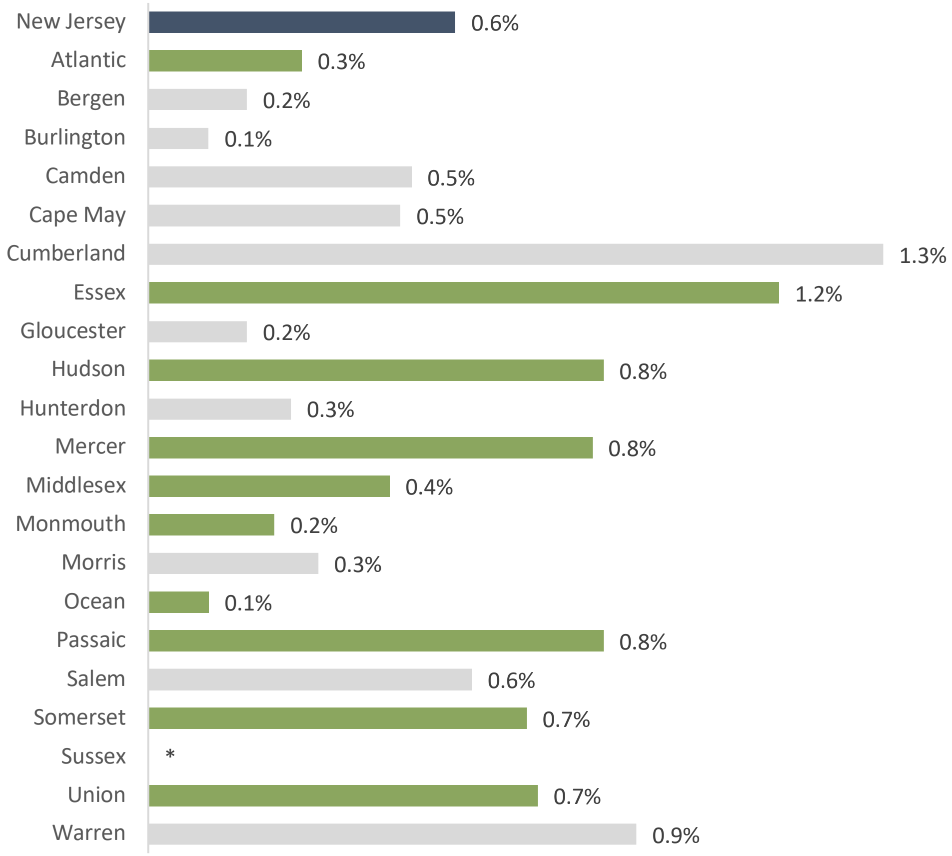
These challenges are attributable to systemic issues such as workforce shortages and low reimbursement as well as lack of training. The consequence, as one interviewee explained, is *“There’s just no place that really wants to deal with [children who have more difficult to control behavior] so they end up in emergency rooms or on pediatric wards where there really aren't people that are appropriately equipped to care for them.”* The recent passage of the Autism Waiver for Medicaid, interviewees explained, has begun to address some of the systemic issues affecting access to mental health services for those with special needs.

While the needs of children with special health care needs dominated conversations about mental health, several participants also spoke about the importance of good mental health for parents/caregivers and other family members, especially siblings. As described earlier, over half of parent/caregiver community survey respondents experienced difficulty maintaining a good mental state since the pandemic. Focus group participants and interviewees listed numerous everyday stresses that parents of special needs children face, including working with schools and healthcare providers, coordinating activities, co-parenting, and managing day-to-day activities for their children such as getting dressed and eating. As one parent explained, *“Some days are smooth, and others aren’t.”* An interviewee who works with many families observed: *“Parents coordinate all this and it’s overwhelming. And if it's gotten to the point of a crisis, it's a family crisis, it's not just the crisis of the acting out behaviorally-challenged child.”*

### Environmental Health

Figure 27 shows that 0.6% of children in the state of New Jersey had elevated blood lead levels between 2016 and 2020. A higher proportion of children in six (Essex, Hudson, Mercer, Passaic, Somerset, and Union) of the ten CSH counties had higher blood lead levels than the state.

**Figure 27: Percent Children with Elevated Blood Lead Levels**

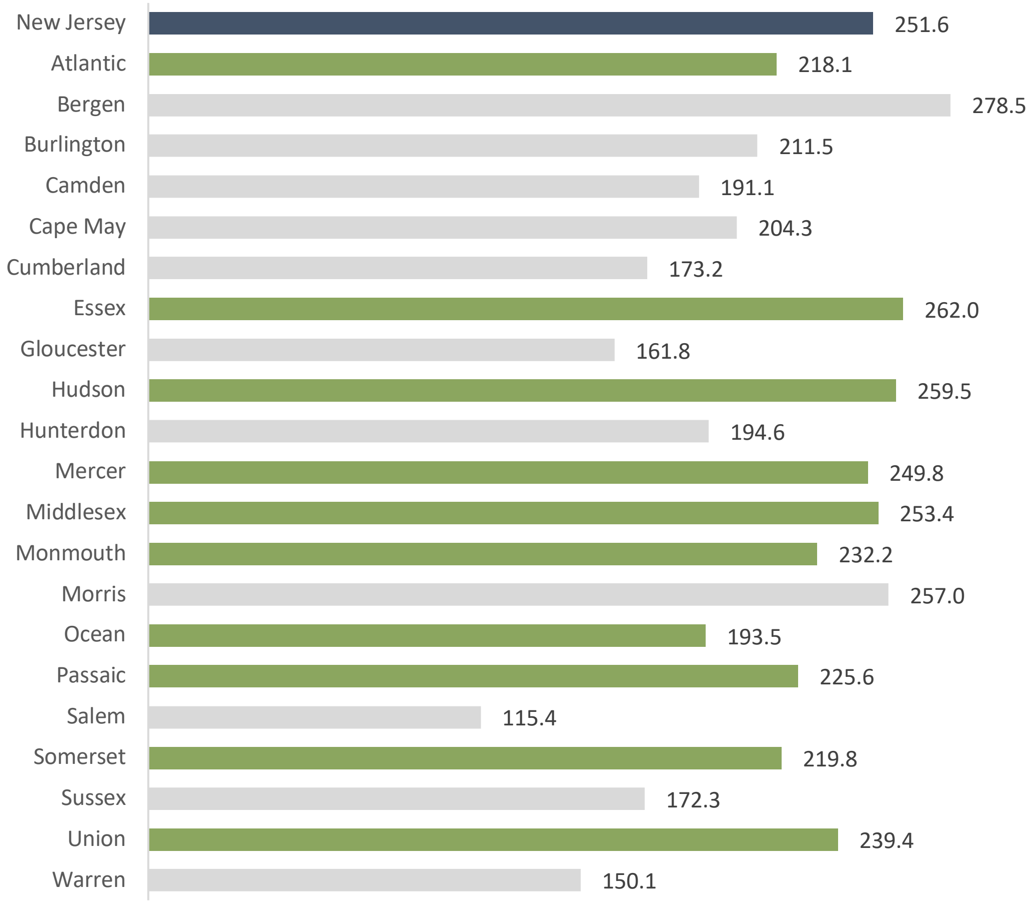


DATA SOURCE: New Jersey State Health Assessment Data (NJSHAD), 2016-2020

### Infectious and Communicable Disease

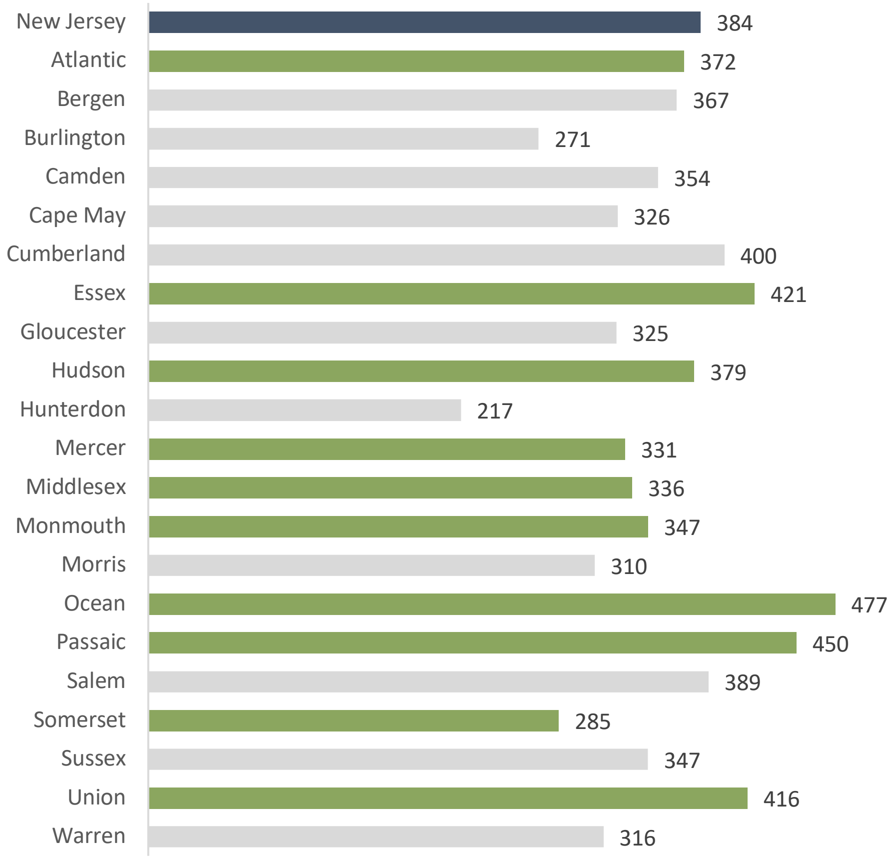
COVID-19 data as of June 2022 are available from the New Jersey Department of Health. These data indicate that 251.6 cases per 100,000 population for New Jersey (Figure 28). Among the counties with CSH locations, three counties (Essex, Hudson, and Middlesex) have higher COVID-19 case rates than the state. As of July 2022, the COVID-19 death in New Jersey was 384 per 100,000 population (Figure 29). Rates in four (Essex, Ocean, Passaic, and Union) of the ten counties with CSH locations were higher than the state.

**Figure 28: COVID-19 Case Rate per 100,000 Population, by State and County, as of 6/30/2022**



DATA SOURCE: New Jersey Department of Health, COVID-19 Activity Report June 30, 2022
NOTE: New Jersey state level data is up to date through July 4, 2022.

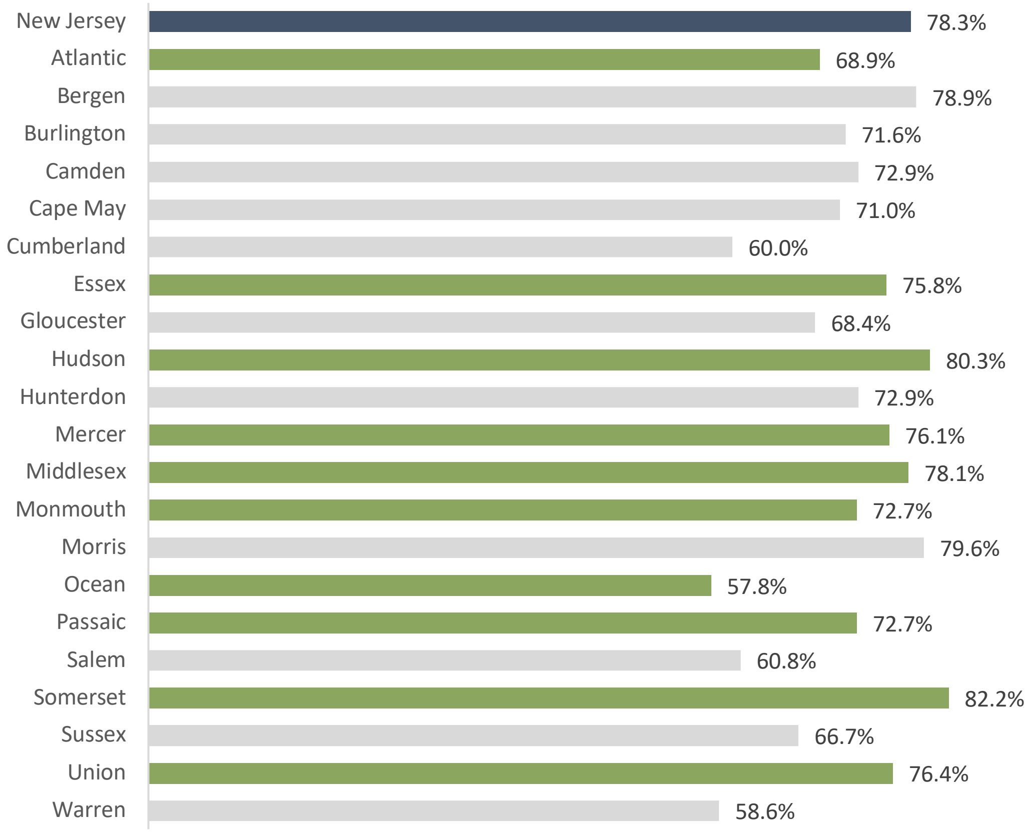
**Figure 29: COVID-19 Death Rate per 100,000 Population, by State and County, as of 7/6/2022**



DATA SOURCE: New Jersey Department of Health, COVID-19 Activity Report June 30, 2022

Data about vaccination show that 78.3% of New Jersey residents over the age of 5 were fully vaccinated as of July 2022 (Figure 30). Two of the ten CSH counties, Hudson and Somerset, have vaccination rates higher than the state.

**Figure 30: Percent Population Over Age 5 Fully Vaccinated, by State and County, as of 7/6/2022**

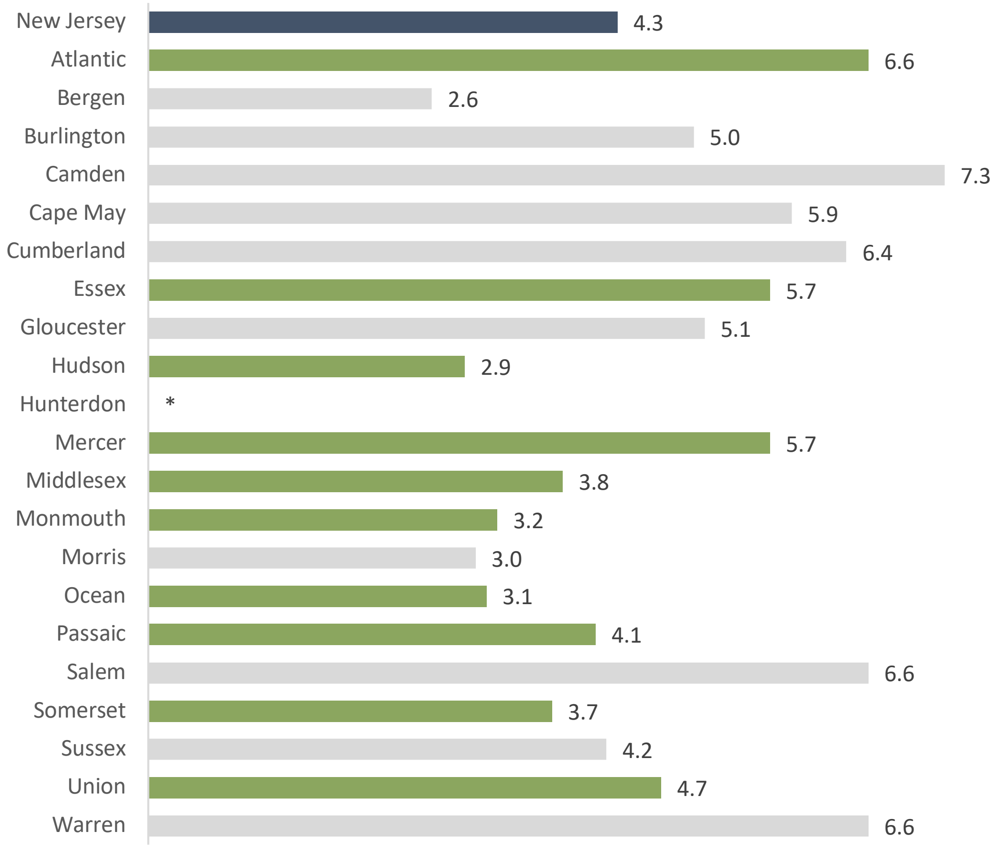


DATA SOURCE: New Jersey Department of Health, COVID-19 Activity Report June 30, 2022

### Maternal and Infant Health

As shown in Figure 31, the infant mortality rate for New Jersey overall was 4.3 per 100,000 births in 2015-2019. Four (Atlantic, Essex, Mercer, and Union) of the ten counties with CSH locations had infant mortality rates higher than the state.

**Figure 31: Infant Mortality Rate per 100,000 Population, by State and County, 2015-2019**

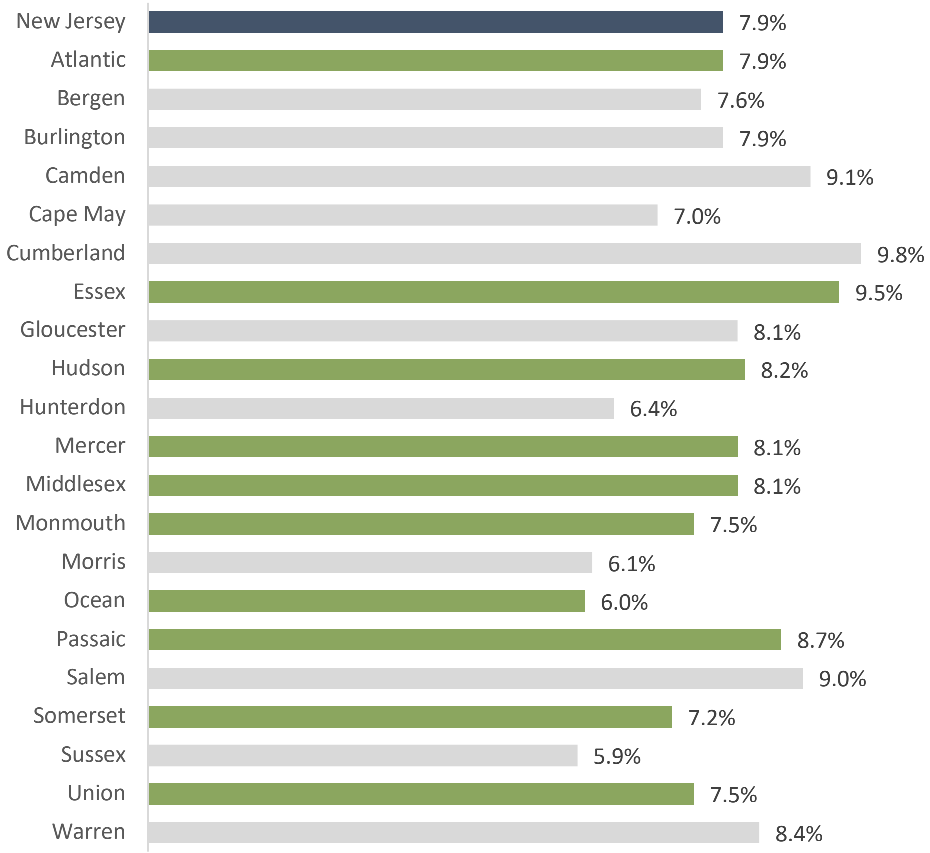


DATA SOURCE: New Jersey State Health Assessment Data (NJSHAD), 2015-2019

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 health care costs and lengths of stay.

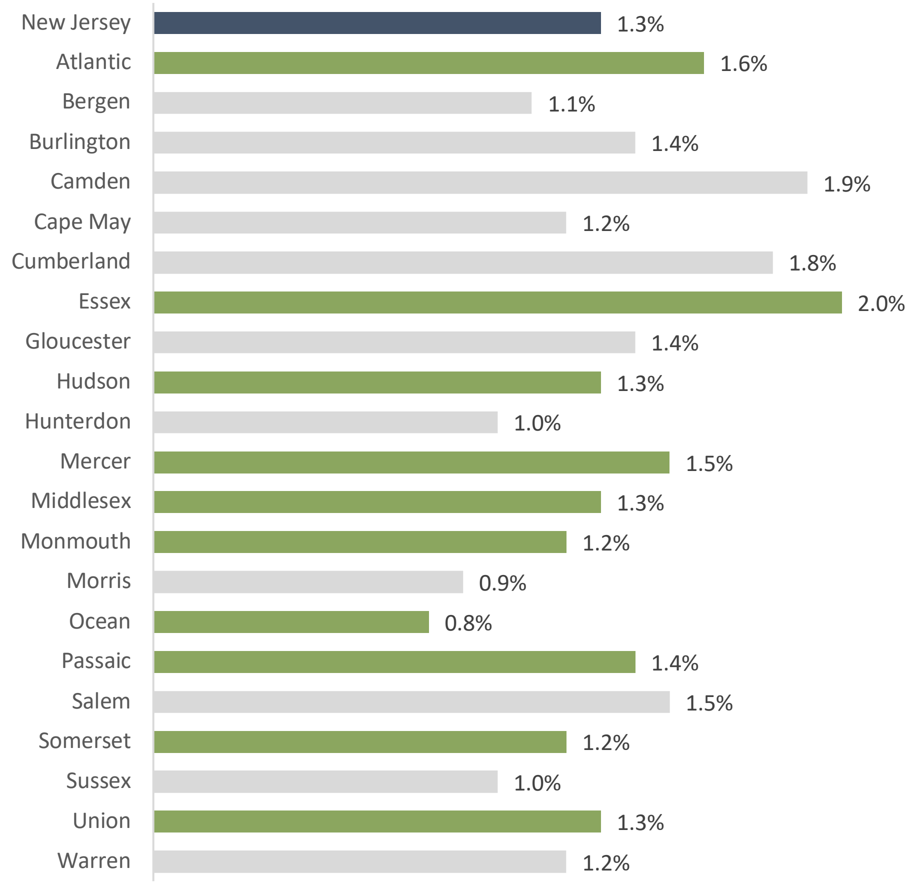
As shown in Figure 32, New Jersey State Health Assessment Data (NJSHAD) from 2016-2020 indicate that 7.9% of births in the state were LBW. Over this same time period, 1.3% of births were classified as very low birthweight (under 1500 grams) (Figure 33). The CSH counties of Essex, Hudson, and Passaic had higher rates of LBW than the state. CSH counties of Atlantic and Essex had higher rates of very low birthweight births than the state.

**Figure 32: Percent Low Birthweight Births, by State and County, 2016-2020**



DATA SOURCE: New Jersey State Health Assessment Data (NJSHAD), 2016-2020
NOTE: Infants weighing under 2500 grams are classified as low birthweight.

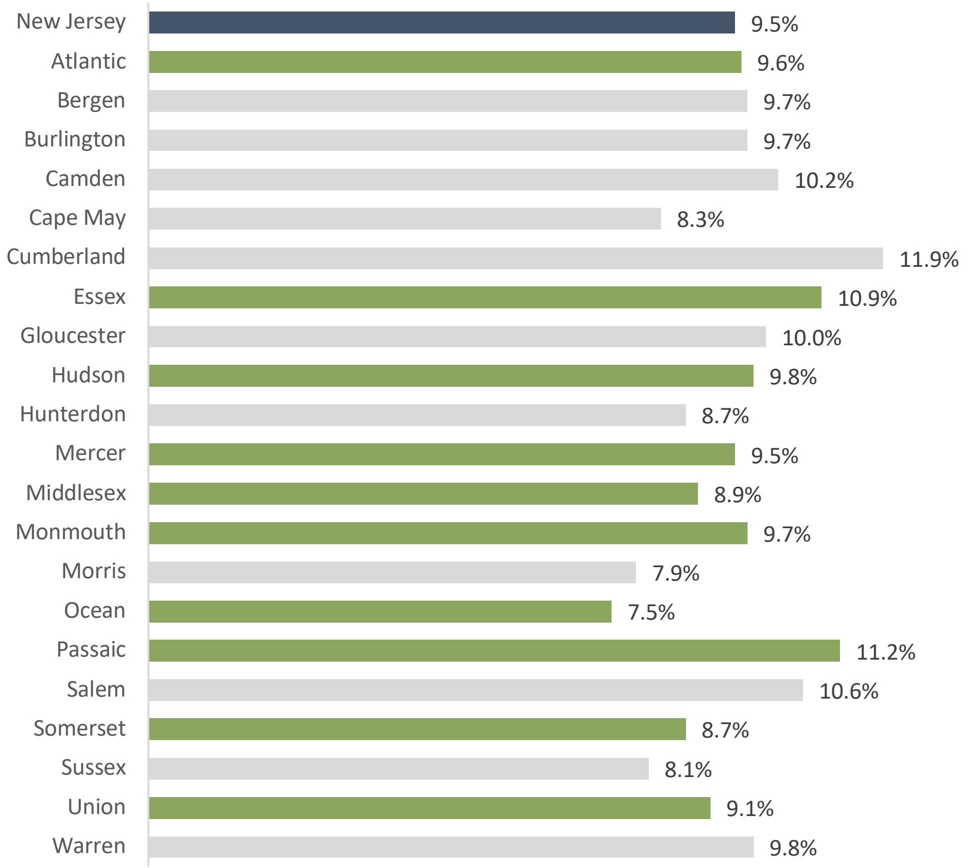
**Figure 33: Percent Very Low Birthweight Births, by State and County, 2016-2020**



DATA SOURCE: New Jersey State Health Assessment Data (NJSHAD), 2016-2020
NOTE: Infants weighing under 1500 grams are classified as very low birthweight.

Data about preterm births, those before 37 weeks, indicate that 9.5% of births in New Jersey from 2016-2020 were preterm (Figure 34). Four (Essex, Hudson, Monmouth, and Passaic) of the ten CSH counties has higher rates of preterm births than the state.

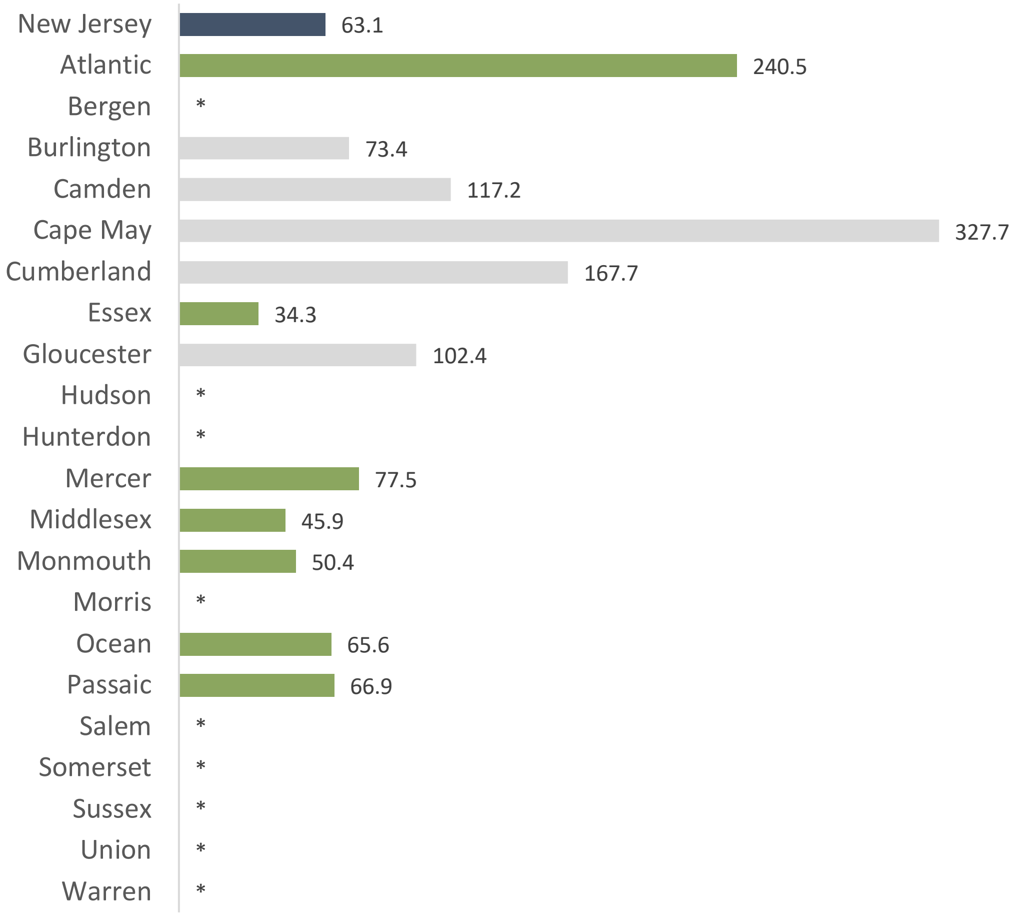
**Figure 34: Percent Preterm Births, by State and County, 2016-2020**



DATA SOURCE: New Jersey State Health Assessment Data (NJSHAD), 2016-2020
NOTE: Infants in gestation for less than 37 weeks.

2019 data about neonatal abstinence syndrome (NAS) from the New Jersey Department of Health indicate that 63.1 births per 10,000 had NAS (Figure 35). Data are not available for all counties; however, among the CSH counties for which data are available, four (Atlantic, Mercer, Ocean, and Passaic) had NAS rates higher than the state. Of all New Jersey counties, Atlantic had among the highest rates, at 204.5 births per 10,000.

**Figure 35: Neonatal Abstinence Syndrome (NAS) Rate per 10,000 Births, by State and County, 2019**



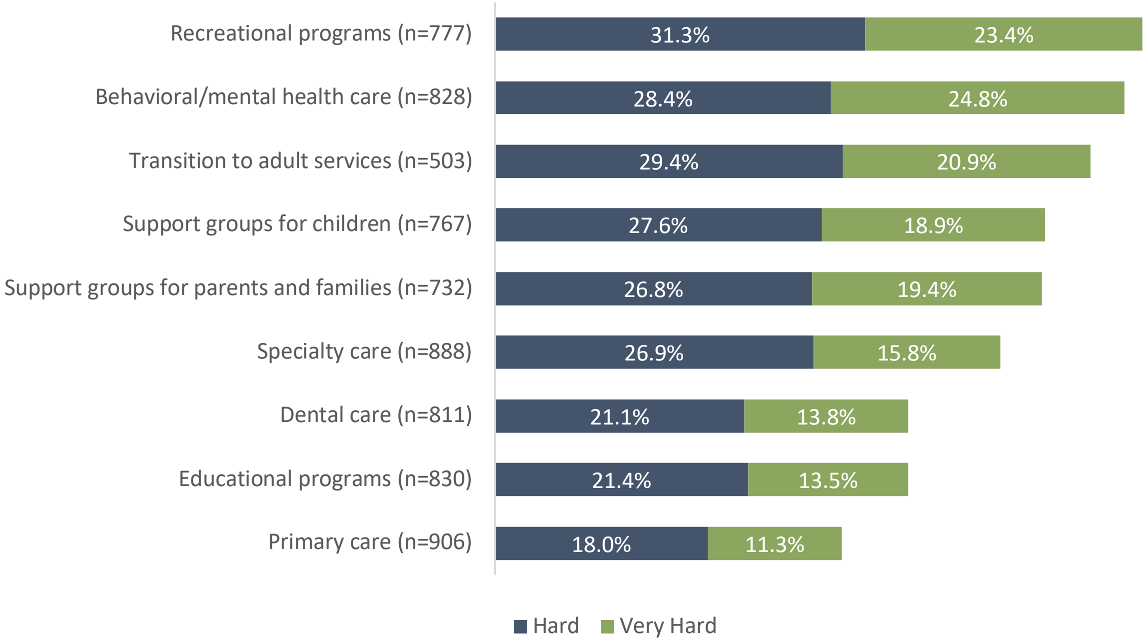
DATA SOURCE: New Jersey Department of Health, 2019
* Data unreliable due to small number of cases.

## 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 health care needs and their families. These include health care 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 by supporting systems and policy change through political action. However, as community survey respondents, parent focus group members, and interviewees reported, some programs and services are difficult to access for a variety of reasons.

Those responding to the community survey were asked how easy or difficult it was to access various health other programs and services for their special needs children. As shown in Figure 36, about half of survey respondents identified recreational programs, behavioral/mental health care, and transition services as very hard or hard to access. Recreational programs were identified as the most difficult to access, perhaps a reflection of the fact that many programs and services were cut back during the pandemic. While sampling limitations preclude statistical comparisons between responses to this survey and those from the community survey conducted for the 2019 CHNA, it is interesting to note that in 2019, among all survey respondents behavioral/mental health services were rated the most difficult to access and transition to adult services were rated the second most difficult. In 2019, recreational programs were the fourth most difficult. Respondents in both 2019 and 2022 rated that same four services—specialty care, primary care, dental care and educational programs—as easier to access among the set of services asked about. Among young adult respondents to the survey (n=19), the programs that were rated as most difficult to access included recreational programs (57.9%), behavioral/mental health services (55.6%), and transition to adult services (53.8%).

**Figure 36. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Health Care Needs, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

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 5 about half of parent/caregiver survey respondents identified recreational programs, behavioral/mental health care, and transition services as very hard or hard to access. In 2019, among parent/caregiver respondents, behavioral/mental health services were rated the most difficult to access and transition to adult services were rated the second most difficult. In 2019, recreational programs were the fourth most difficult.  Similar to parent/caregiver respondents, over half of survey respondents who are involved in the lives of children with special health care needs in other ways (as other family member, friend, or someone who works with children) identified transition to adult services, behavioral/mental health care, and recreational programs as very hard or hard to access for children with special health care needs. In contrast to parent/caregiver respondents, these respondents rated dental care as the most difficult service to access. In 2019, community survey respondents who were not parents/caregivers rated transition to adult services as most difficult to access and access to behavioral/mental health services as the second most difficult. As in 2022, other respondents also identified dental care as difficult to access in 2019: in 2019 it was rated the third most difficult service for families with special needs children to access.

**Table 5. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Health Care Needs, among Parents/Caregivers and Other Respondents, 2022**

| | Parents/Caregivers (n=891) | Other Respondents (n=65) |
|---|---|---|
| 1 | Recreational programs (54.9%) | Dental care (57.2%) |
| 2 | Behavioral/mental health care (50.3%) | Transition to adult services (56.1%) |
| 3 | Transition to adult services (49.5%) | Behavioral/mental health care (55.4%) |
| 4 | Support groups for parents and families (46.9%) | Recreational programs (52.5%) |
| 5 | Support groups for children (46.9%) | Specialty care (46.7%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Responses varied by different survey respondents. While challenges accessing recreational and behavioral/mental health programs were top two concerns for non-Hispanic Asian, non-Hispanic White, and Hispanic parent/caregiver respondents, transition to adult services were the top challenge for Black respondents and those who identified as other or multiracial (Table 6).

**Table 6. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, by Race/Ethnicity, 2022**

| | Black/African American, NH (n=78) | Asian, NH (n=27) | White, NH (n=281) | Hispanic/ Latino(a) (n=233) | Other/ Multiracial (n=35) |
|---|---|---|---|---|---|
| 1 | Transition to adult services (56.8%) | Recreational programs (60.9%) | Behavioral/ mental health care (59.6%) | Recreational programs (57.3%) | Transition to adult services (43.5%) |
| 2 | Recreational programs (44.9%) | Behavioral/ mental health care (60.9%) | Recreational programs (55.7%) | Behavioral/ mental health care (51.3%) | Behavioral/ mental health care (51.3%) |
| 3 | Support groups for parents and families (39.1%) | Support groups for children (54.6%) | Support groups for children (49.0%) | Transition to adult services (48.7%) | Recreational programs (38.7%) |
| 4 | Support groups for children (38.9%) | Specialty care (53.6%) | Specialty care (48.8%) | Support groups for parents and families (47.4%) | Support groups for parents and families (36.7%) |
| 5 | Behavioral/ mental health care (37.0%) | Support groups for parents and families (47.8%) | Support groups for parents and families (48.7%) | Support groups for children (44.4%) | Support groups for children (32.3%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Challenges accessing behavioral/mental health and recreational programs were among top challenges for parent/caregiver survey respondents regardless of insurance (Table 7). Respondents with private insurance were more likely to report challenges accessing specialty care than those with public insurance.

**Table 7. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, by Insurance Status, 2022**

| | Private Insurance (n=239) | Public Insurance (n=401) |
|---|---|---|
| 1 | Behavioral/ mental health care (64.4%) | Recreational programs (53.6%) |
| 2 | Recreational programs (55.9%) | Behavioral/ mental health care (47.9%) |
| 3 | Support groups for parents and families (55.8%) | Transition to adult services (46.3%) |
| 4 | Transition to adult services (52.8%) | Support groups for parents and families (43.6%) |
| 5 | Specialty care (52.5%) | Support groups for children (43.5%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Table 8 shows parent/caregiver responses by age of children with special health care needs. While many of the same programs and services were identified as hard or very hard to access across parents/caregivers with special needs children of different age groups, the proportion of respondents reporting these challenges differed. Overall, a higher proportion of parents/caregiver respondents with children over age 18 reported that these programs and services were hard or very hard to access. Notably, about two-thirds of parent/caregiver respondents with older special needs children reported that behavioral/mental health care and recreational programs were hard or very hard to access for their children. This is consistent with perspectives shared by interviewees and parent focus group members who reported that there are fewer programs and services available for older youth and young adults with special health care needs. Parents/caregiver respondents of tween and teen children with special health care needs were more likely to report challenges accessing specialty care than parents/caregiver respondents with children of other ages.

**Table 8. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, by Age of Child, 2022**

| | Under 5 years (n=134) | 5 -9 years (n=196) | 10-14 years (n=170) | 15-18 years (n=62) | Older than 18 years (n=64) |
|---|---|---|---|---|---|
| 1 | Recreational programs (58.3%) | Recreational programs (57.1%) | Behavioral/ mental health care (55.1%) | Behavioral/ mental health care (49.1%) | Behavioral/ mental health care (69.6%) |
| 2 | Behavioral/ mental health care (49.6%) | Support groups for parents and families (48.2%) | Recreational programs (47.7%) | Specialty care (45.25%) | Recreational programs (64.4%) |
| 3 | Support groups for parents and families (45.5%) | Behavioral/ mental health care (47.8%) | Specialty care (46.5%) | Recreational programs (43.47%) | Support groups for children (64.2%) |
| 4 | Support groups for children (42.3%) | Support groups for children (45.5%) | Support groups for children (45.2%) | Support groups for parents and families (43.1%) | Transition to adult services (62.7%) |
| 5 | Transition to adult services (36.4%) | Transition to adult services (45.4%) | Support groups for parents and families (44.8%) | Transition to adult services (49.1%) | Support groups for parents and families (56.9%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

### Access to Health Care Services

As described, above, while parents and caregivers responding to the community survey reported the most difficulty accessing recreational programs, behavioral/mental health services, and transition services for their children with special needs, they also reported difficult accessing healthcare, especially specialty care. About 42% reported that accessing specialty care for their children was “very hard” or “hard” and 29% reported similarly for primary care. Parent/caregiver respondents who were non-Hispanic Asian and non-Hispanic White, who had private insurance, and who had children between the ages of 10 and 18 were more likely to report difficulty accessing specialty care than other groups. Parent focus group participants and interviewees likewise reported challenges accessing these services.

Data from the National Survey of Children’s Health show that in 2019-2020, a smaller proportion of children with special health care needs than other children received care within a medical home, both in New Jersey and nationwide (Table 9). In New Jersey, 40.8% of children with special healthcare needs received care in a medical home, compared to 47.5% of other children.

**Table 9: Percent Children Aged 1-17 Who Received Care Within a Medical Home, by Special Health Care Needs Status, by US and New Jersey, 2019-2020**

| | CSHCN | Non-CSHCN |
|---|---|---|
| United States | 42.2% | 47.9% |
| New Jersey | 40.8% | 47.5% |

DATA SOURCE: National Survey of Children's Health, 2019-2020
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.

Consistent with community survey findings, data from the National Survey of Children's Health shows that a substantially higher proportion of families of children with special health care needs reported difficulties accessing specialist care in 2019-2020, both in New Jersey and nationally (Table 10). In New Jersey, 7.5% of parents of children with special health care needs reported difficulties, compared to 2.4% of other parents.

**Table 10: Percent Families Reporting Difficulties Obtaining Specialist Care, by Special Health Care Needs Status, by New Jersey, 2019-2020**

| | CSHCN | Non-CSHCN |
|---|---|---|
| United States | 10.3% | 4.9% |
| New Jersey | 7.5% | 2.4% |

DATA SOURCE: National Survey of Children's Health, 2019-2020
NOTE: Data shown combines responses "somewhat difficult", "very difficult", or "it was not possible to obtain care". "Very difficult" and "not possible" estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable.

Quantitative data from the National Survey of Children's Health indicate that in 2019-2020, a higher proportion of children with special health care needs than other children received a preventative dental visit (Table 11). In 2019-2020, 84.8% of children with special health care needs in New Jersey had a dental check-up, compared to 81.1% of other children.

**Table 11: Percent Children Aged 1-17 Who Received a Preventative Dental Visit, by Special Health Care Needs Status, by US and New Jersey, 2019-2020**

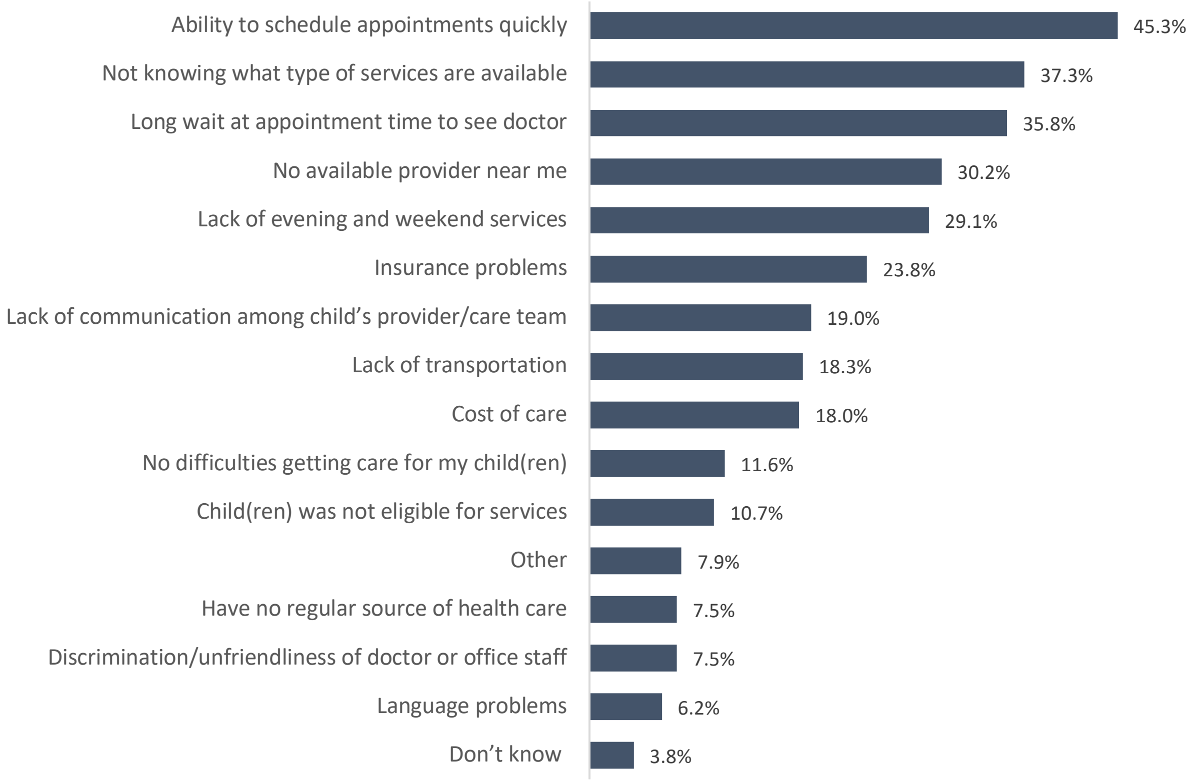
| | CSHCN | Non-CSHCN |
|---|---|---|
| United States | 81.9% | 76.4% |
| New Jersey | 84.8% | 81.1% |

DATA SOURCE: National Survey of Children's Health, 2019-2020

**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 (45.3%), not knowing what services are available (37.3%), and long wait at appointment time to see doctors (35.8%) (Figure 37). In 2019, parent/caregiver respondents identified insurance problems as the biggest barrier to accessing health care for their children with special health care needs, followed by lack of evening and weekend services, and not knowing what types of services are available. As in 2022, far fewer respondents reported issues such as language barriers, no regular source of healthcare, or discrimination/ unfriendliness of providers' offices in 2019.

**Figure 37. Percent of Community Survey Respondents Reporting Issues that Make It Difficult to Access Health Care for Children with Special Health Care Needs, among Parents/Caregivers, n=874, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

As Table 12 shows, respondents from different racial/ethnic groups reported different challenges. Asian and Other/Multiracial respondents were more likely than other groups to report lack of weekend and evening hours as a barrier to accessing healthcare while parent/caregiver respondents who self-identified as Black, White, and Hispanic/Latino were more likely to report challenges scheduling appointments quickly. Lack of transportation was noted as a top barrier for parent/caregiver respondents who identified as Asian or Other/Multiracial.

**Table 12. Percent of Community Survey Respondents Reporting Issues That Make It Difficult to Access Health Care for Their Children with Special Health Care Needs, among Parents/Caregivers, by Race/Ethnicity (N=669), 2022**

| | Black/African American, NH (n=81) | Asian, NH (n=27) | White, NH (n=286) | Hispanic/ Latino(a) (n=239) | Other/ Multiracial (n=36) |
|---|---|---|---|---|---|
| 1 | Ability to schedule appointments quickly (33.3%) | Lack of evening/weekend services (51.9%) | Ability to schedule appointments quickly (51.4%) | Ability to schedule appointments quickly (46.9%) | Knowing what services are available (36.4%) |
| 2 | Knowing what services are available (32.1%) | Long wait at appointment time (40.7%) | Long wait at appointment time (43.4%) | Knowing what services are available (41.0%) | Lack of evening/weekend services (32.5%) |
| 3 | Lack of evening/weekend services (25.9%) | No providers near me (40.7%) | Knowing what services are available (36.4%) | Long wait at appointment time (34.3%) | Ability to schedule appointments quickly (51.4%) |
| 4 | Long wait at appointment time (22.2%) | Ability to schedule appointments quickly (37.0%) | No providers near me (36.0%) | No providers near me (30.5%) | Lack of transportation (21.0%) |
| 5 | Lack of transportation (21.0%) | Knowing what services are available (33.3%) | Lack of evening/weekend services (32.5%) | Lack of evening/weekend services (24.3%) | Long wait at appointment time (43.4%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

As shown in Table 13, parent/caregiver respondents with private insurance reported similar top challenges to accessing healthcare as those with public insurance, with two exceptions: Those with private insurance were more likely to report lack of evening/weekend services as a top barrier. while those with public insurance were more likely to report lack of transportation as a top barrier.

**Table 13. Percent of Community Survey Respondents Reporting Issues That Make It Difficult to Access Health Care for Their Children with Special Health Care Needs, among Parents/Caregivers, by Insurance Status (N=662), 2022**

| | Private Insurance (n=259) | Public Insurance (n=403) |
|---|---|---|
| 1 | Ability to schedule appointments quickly (54.8%) | Ability to schedule appointments quickly (43.4%) |
| 2 | Long wait at appointment time (44.0%) | Knowing what services are available (40.2%) |
| 3 | Lack of evening/weekend services (37.5%) | Long wait at appointment time (33.3%) |
| 4 | Knowing what services are available (33.3%) | No providers near me (29.8%) |
| 5 | No providers near me (32.8%) | Lack of transportation (24.3%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

*Finding Providers*

As described above, barriers to accessing healthcare among parent/caregiver survey respondents included difficulty of scheduling appointments quickly, no providers nearby, lack of awareness about available services, and lack of evening and weekend services.

> *"The wait list to see a developmental pediatrician is about six months and when you're talking about something like autism, we know you need to intervene right away so that you get optimal care. And that is not going to happen unless you're rich, so the disparities are remarkable."* – Key informant interviewee

Parent focus group participants and interviewees cited lack of providers, especially those in some key areas, as a substantial challenge for families with special needs children. They frequently mentioned a lack of developmental behavioral pediatricians, who play an important role in conducting the assessments needed to access further services. One interviewee stated, "*Families should not have to wait over a year to get an appointment for an evaluation to determine a diagnosis. While waiting for that diagnosis the child is missing out on critical services that they should be entitled to."* According to participants and open-ended comments from survey respondents, other areas with too few providers and long wait times for appointments include pediatric surgery, therapies (OT, PT, speech), and dental care. As one survey respondent wrote, *"My little girl is receiving speech therapy every week, but she had to wait six months to receive the first one, and I think that is a lot."*

Finding providers for transition-age young adults was reported to be challenging as these patients are no longer able to access services through children's hospitals. Finding community-based services such as intensive outpatient programs (IOP) or in-home supports was also reported to be challenging. A shortage of providers leads to inequitable access to care, as several interviewees described. One person stated, *"There are waitlists and difficulty with developmental and psychiatric evaluation. If you have money, you can get in the top of the line."*

Participants and survey respondents also reported that families of children with special healthcare needs must often travel to get healthcare for their children, particularly specialty care, which can be challenging with a special needs child. While telehealth has been a solution for some parents, others noted that virtual medical appointments do not work for their children.

*Finding Providers with Special Needs Experience*

A common theme in conversations with parents and interviewees was health care professionals without sufficient training to work with patients who have more complex health challenges. As one person commented, *"Primary care physicians are generalists and don't always have up-to-date information on children with special needs."* Others shared similar perspectives on a variety of healthcare providers, including dentists, emergency departments, and specialists. As one parent shared, it can take more time and patience to have a special needs child sit for a dental exam, for example, and *"most dentists don't know how to handle panic attacks or sensory issues while doing a cleaning or dental work."*

Further, parents reported that they are often dismissed by providers when discussing the health of their children. One parent shared, "*My daughter has a fairly rare condition, and I can't tell you the number of times doctors have corrected us. Some of us know what we're talking about."* An interviewee echoed this view saying, *"Hospital and medical settings don't have the depth of knowledge and don't value the role of the parent as an informant."* Parents stated that providers' lack of understanding of special needs children and dismissal of parents' knowledge of their children can negatively impact the quality of care their children receive. They stated that some physicians are quick to make assumptions about their children, attributing physical health challenges to behavioral issues. For example, one focus group participant stated, *"I've had problems with a GI specialist; they will chalk it all up to behavior. 'Oh, he has autism, it's just behavior why he can't go to the bathroom.'"* Interviewees saw a need for health care that is disability-informed and recognizes and respects parents' knowledge. As one stated: *"Other physicians need to understand there's so many different layers to what you're seeing when you have a child with special health care needs. A neurotypical child may not need so many other avenues of support when they're going in just for something like allergies."*

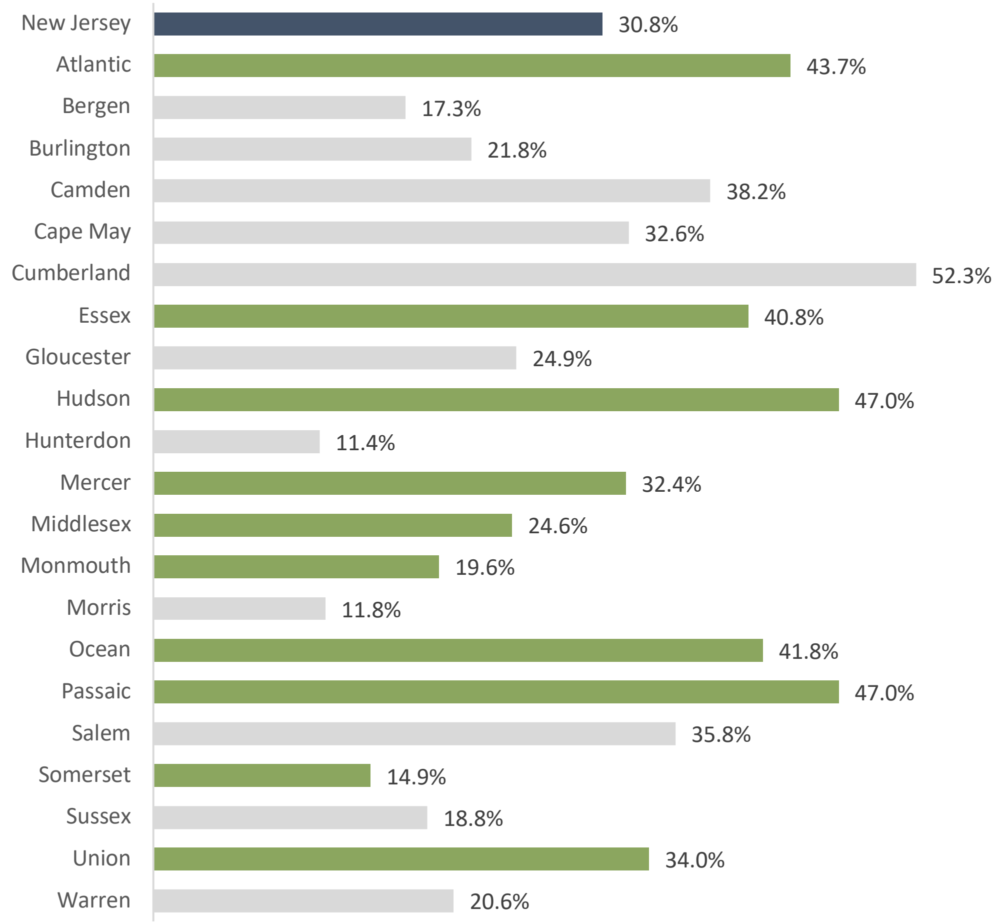
> *"We hear stories like families who go to the ER go to a doctor's office and their opinions are not taken into consideration. What they have to say about their child, the person who knows best, is just not part of the conversation with the physician who thinks they, because they have the training, know best. And then children get inappropriately restrained, medical attention is not administered as effectively, and or misdiagnosed."* –Key informant interviewee

### Insurance Acceptance and Coverage

About one quarter of parent/caregiver respondents to the community survey cited insurance problems as a barrier to accessing health care for their children with special health care needs (data shared in Appendix E). Parent focus group participants and interviewees also mentioned challenges with health insurance. Several parents reported that it can be difficult to find providers who accept some insurances, especially Medicaid. One community survey respondent wrote, *"Some physicians don't accept some government insurances. It causes difficulties to find a provider in specialties such as audiologist, genetics counseling, ophthalmologist, etc."* One interviewee noted that many subspecialists do not accept Medicaid and a growing number are not accepting Medicare. As this person stated, *"Access to particular subspecialty providers can be extraordinarily difficult."* Parent and caregiver survey respondents also shared that limitations on insurance coverage for some services is a challenge for families with special needs children. One person wrote, *"In our case, even covered, we had to pay over $1,400 for four months of PT. We can't afford to continue therapy if we have to pay this much."*

According to American Community Survey data, in 2016-2020, 30.8% of children under age 19 in New Jersey were enrolled in Medicaid (Figure 38). The proportion of children under 19 enrolled in Medicaid is above the state average in seven of the ten CSH counties (Atlantic, Essex, Hudson, Mercer, Ocean, Passaic, and Union). According to the 2019-2020 National Survey of Children's Health 35.4% of children in New Jersey with special health care needs ages 1-17 are enrolled in public health insurance, compared to 24.0% of other children (Table 14). This mirrors national statistics.

**Figure 38: Percent Children Under 19 Enrolled in Medicaid, by State and County, 2016-2020**



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2016-2020

**Table 14. Percent Children Aged 1-17 Enrolled in Public Health Insurance, by Special Health Care Needs Status, by New Jersey, 2019-2020**

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

DATA SOURCE: National Survey of Children's Health, 2019-2020
NOTE: “Public insurance” is defined as "Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability."

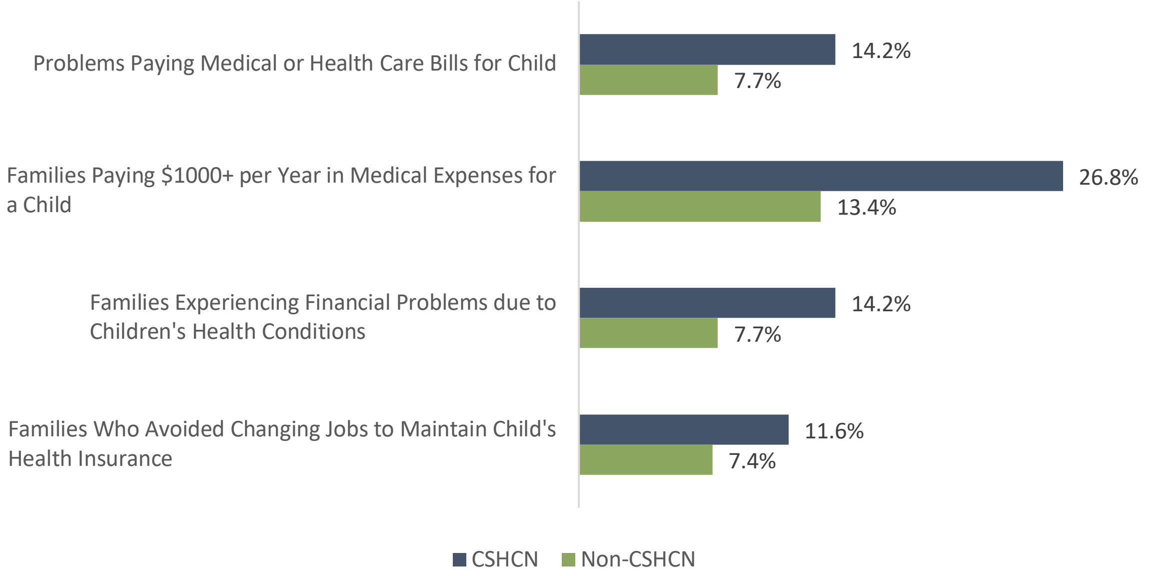
*Cost*

Meeting the needs of a child/children with special health care needs can be costly for families. Several focus group participants and interviewees and about 18% of parent/caregiver respondents to the community survey identified the cost of health care and related services for children with special needs as a challenge (data in Appendix E). Several participants shared that lower income families face more challenges than higher income families. As one person stated, *“It’s a huge barrier for families who are low income, either public insurance or those who are lost in the gap between the employed but too much* *money for Medicaid, single parent family or working in entry level jobs that don't permit them to take time off."* Higher income families, participants noted, have access to more services and specialists and have more resources at hand to access other services and programs for their children.

> *"We haven't had a problem [accessing healthcare] because we have the ability to travel and pay for what [our child] needs. We also have good insurance. Very different from most parents."* – Community survey respondent

The National Survey of Children's Health provides a quantitative picture of the financial challenges for families with special needs children. In 2019-2020, a far higher proportion of families with children with special health care needs reported problems paying medical or health care bills and paying over $1,000 in medical expenses for their children, compared to other families (Figure 39). These families were also more likely to report that they had experienced financial problems due to their children's conditions. The proportion of families reporting that they paid more than $1,000 a year in medical expenses for their child and who experienced financial problems due to their children's health conditions was twice as high as for other families, 26.8% compared to 13.4% and 14.2% compared to 7.7%, respectively. Additionally, 11.6% of parents of special needs children reported that they had avoided changing jobs to maintain their child's health insurance, compared to 7.4% for other families.

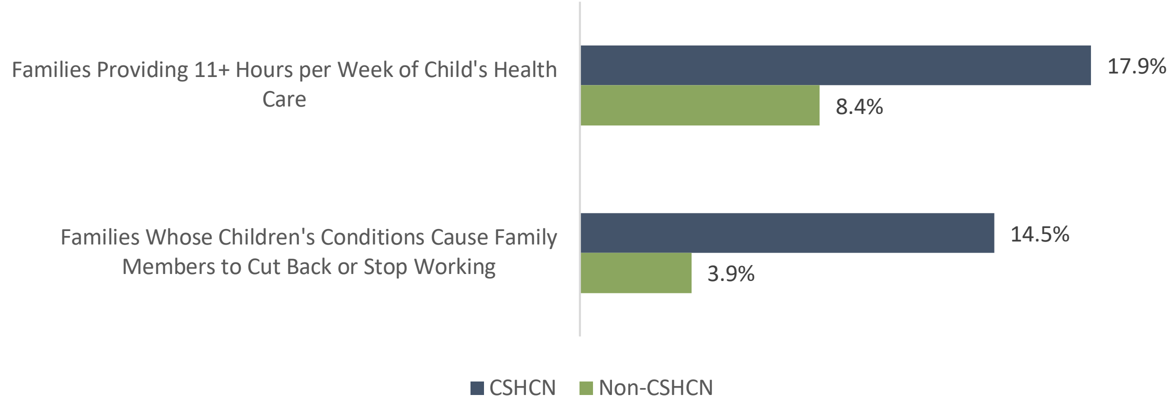
**Figure 39: Percent Families Reporting Financial Challenges, by Special Health Care Needs Status, by New Jersey, 2019-2020**



DATA SOURCE: National Survey of Children's Health, 2019-2020

Figure 40 shows that the percentage of New Jersey parents of children with special health care needs reporting they spent 11 or more hours per week providing or coordinating care is over twice as high (17.9%) than other families (8.4%). The proportion of families with special needs children reporting that their children's conditions caused family members to cut back or stop working was over three times higher (14.5%) than for other families (3.9%).

**Figure 40: Percent Families Providing 11+ Hours per Week of Child's Health Care and Whose Children's Conditions Cause Family Members to Cut Back or Stop Working, by Special Health Care Needs Status, by New Jersey, 2019-2020**



DATA SOURCE: National Survey of Children's Health, 2019-2020

*Care Coordination*

A frequent topic in conversations with parents and interviewees was the issue of care coordination. Professionals engaged with special needs children, interviewees shared, tend to focus on their particular locus of responsibility, with little communication with other professionals. As a result, parents often find themselves coordinating and communicating across systems.

> *"If my developmental pediatrician is referring me to a speech pathologist, I shouldn't have to go in there and reiterate everything that they're referring me to be there for. The parent is the translator across specialists, even within the same health system."*– Key informant interviewee

As the parent of a special needs child shared, *"I needed to create a support system around this kid where everyone had communication and if I needed to be that that person in the middle, which I am and it's fine, I was going to ensure that everyone had a piece of everyone's information."* While care coordinators or case managers exist—such as through insurance, at schools, or through New Jersey's Children's System of Care initiative—their level of expertise and engagement varies and turnover in these positions is high, interviewees and parents reported. Sometimes, parents have to coordinate across these as well, as one person explained, "*There are an awful lot of people who are labeled case manager, care manager and you can have three to five of those depending on how young your child is or your older emerging adult."* This can be overwhelming for parents. One interviewee stated, *"I think one of the biggest mistakes that parents make is you're fighting for so much of the related services—OT, PT, and speech—but it's not done comprehensively."*

**Use and Perceptions of Telehealth**

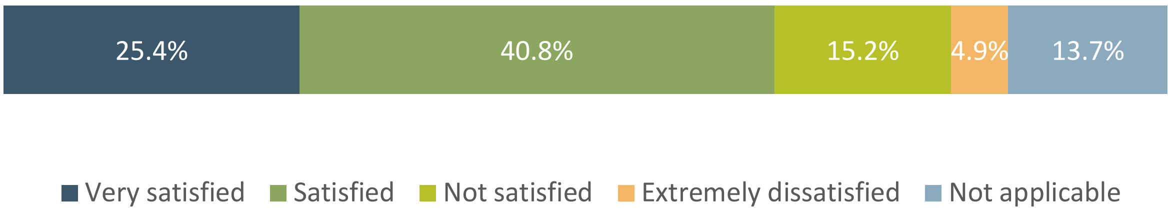
The COVID-19 pandemic accelerated the adoption of telehealth to deliver medical services. Experiences with and thoughts about telehealth varied across interviewees and among parents and caregivers responding to the community survey.

Figure 41 provides data from parent/caregiver survey respondents relative to satisfaction with and openness to using telemedicine. One quarter of the 618 parent/caregiver survey respondents answering this question reported that they were “very satisfied” while another 40% reported that they were “satisfied” with their use of telehealth. About 20% reported that they were “not satisfied” or “extremely dissatisfied.” Satisfaction was slightly higher among Asian and Other/Multiracial survey respondents when compared to other racial and demographic groups and slightly higher among those who are publicly insured compared to those privately insured (Table 15). Survey respondents as well as parent focus group participants who reported positive experiences with telehealth often cited the convenience of not having to travel and the ability to better schedule around work obligations. For other families, however, being on a screen does not work for their children—they do not interact well on screen or need frequent re-direction. Some families face challenges accessing technology. Participants also acknowledged that telehealth works better for well child visits and less well for OT and PT appointments.

*“You don’t have to worry about getting in the car and driving to the office. It’s a lot easier especially when you have an autistic child that hates going in the car or doctors.”*
– Community survey respondent

*“My son has sensory issues and if he is asked to speak to someone on a screen he flips out, yells, tries to break the computer etc.; it’s a nightmare.”* – Community survey respondent

**Figure 41. Percent of Community Survey Respondents Indicating Their Level of Satisfaction with Use of Telehealth, among Parents/Caregivers, (n=618), 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

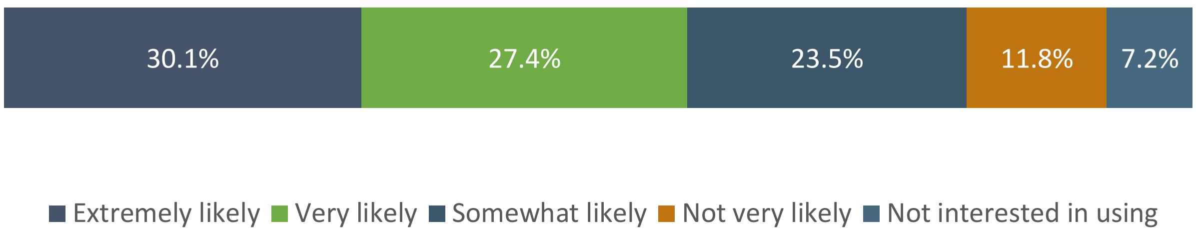
**Table 15. Percent of Community Survey Respondents Very Satisfied/Satisfied with Use of Telehealth, among Parents/Caregivers, by Race/Ethnicity (n=657) and Insurance Status (n=639), 2022**

| | % Very satisfied/Satisfied |
|---|---|
| Race/Ethnicity | |
| Black/African American, NH (n=81) | 66.6% |
| Asian, NH (n=28) | 78.6% |
| White, NH (n=280) | 65.4% |
| Hispanic/Latino(a) (n=233) | 67.8% |
| Other/Multiracial, NH (n=35) | 74.3% |
| Insurance Status | |
| Private health insurance (n=247) | 60.8% |
| Government plan (n=392) | 68.9% |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

About 30% of parent/caregiver survey respondents reported that they would be “extremely likely” to use telehealth for their child with special health care needs if needed and they were able to access it, while another 27.4% reported that they would be “very likely” to do so (Figure 42). Black and Asian survey respondents were more likely to report this than other racial and demographic groups (Table 16).

**Figure 42. Percent of Community Survey Respondents Indicating Their Likelihood of Using Telehealth for Their Child with Special Health Care Needs if Needed and Able to Access, among Parents/Caregivers, n=752, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Table 16. Percent of Community Survey Respondents Extremely Likely/Very Likely to Use Telehealth for Their Child with Special Health Care Needs if Needed and Able to Access, among Parents/Caregivers by Race/Ethnicity (n=657) and Insurance Status (n=639), 2022**

| | % Extremely Likely/ Very Likely |
|---|---|
| Race/Ethnicity | |
| Black/African American, NH (n=81) | 64.2% |
| Asian, NH (n=28) | 60.7% |
| White, NH (n=280) | 58.0% |
| Hispanic/Latino(a) (n=233) | 55.1% |
| Other/Multiracial, NH (n=35) | 59.5% |
| Insurance Status | |
| Private health insurance (n=247) | 54.3% |
| Government plan (n=392) | 58.8% |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

### Access to Other Services for Children with Special Health Care Needs and their Families

The following section describes the themes that emerged in accessing other services for children with special health care needs including programs for children and youth, transition services, respite and long-term care, and programs and supports for families.

*Programs for Children and Youth*

As described earlier, interviewees, survey respondents, and parent and youth focus group participants reported that New Jersey's communities have a variety of programs for children and youth with special health care needs including sports, recreation, and educational programs and support groups. The greatest value of these programs, according to parent and youth focus group members and community survey respondents, is socialization. These programs provide young people an opportunity to have fun and get to know others who are like them. Through field trips and community service opportunities, these programs also enhance children and youth participation in the community. As noted in the community survey, many parent and caregiver respondents find it very hard or hard to access these programs: over half reported difficulty accessing recreational programs and nearly half reported difficulty accessing support groups for their children.

*Transition Services*

The process of transitioning from school to adulthood at about age 21 was a frequent topic of conversation in interviews and the parent focus group. It was a prominent theme in the community survey as well.  This period in a child's life was described as an overwhelming time for parents with special needs children: they must make decisions about guardianship; plan and complete paperwork to transition from youth to adult program services and benefits; plan for their children's pathway after school; and move their children from pediatric health care to adult providers. Each of these, interviewees and parents

> *"[Parents] are just living day-to-day. And then you've got that cliff [of transition age]. It appears and you're gonna go falling off if you haven't had some steps in place."* – Key informant interviewee

explained, is complex and parents' planning and capacity to do these things varies. As one interviewee observed, *"I've had some families where the child is 21 and [parents] still haven't had guardianship and then I have other families where the child is 17 and a half and I'm already getting the forms to complete."*

Parent focus group members, interviewees, and community survey respondents noted that lack of services for transition-age youth is a substantial barrier. About half of parent/caregiver survey respondents indicated that services to support transition to adult services are very hard or hard to access.

School districts provide a variety of supports for transition at age 21 (currently 22 due to closures during COVID). They often provide classes for the tasks of daily living and structured learning experiences (also called work-based learning) for young people ages 18 to 21, to expose them to job opportunities and get them involved in the community. However, after students leave the school system, fewer opportunities are available. While many young people are connected to Vocational Rehabilitation services which provide coordination services and money for college classes, job coaching, and job support, not all are. Planning for these next steps is critical, but parents noted that getting information to support them with this planning can sometimes be difficult. One survey respondent shared, *"I ask [about planning for the future] and nobody knows the answer or somebody's busy and won't return my calls. I'm asking to know what lies in the future for me and they're too busy dealing with what's going on right now."*

The quality of these services depends on person, and participants reported that staff turnover in these positions is high which can make continuity difficult. Yet staying connected to services in young adulthood and beyond is critical as one interviewee explained: *"I think maintenance is huge: how do we maintain the skills. It's so much harder when they are adults and there are not the small ratios of support. They've lost some language. They were doing things for themselves in these programs, but now are not supported with this. That is going to impact the quality of life."*

Another challenge, parents and interviewees reported, is that transition age youth typically have to "graduate" from recreational and other programs that have connected them to a social network, often over many years. This can mean that they lose touch with friends and have to start over again making new ones. Parents reported that there are fewer programs for young adults to get together with others, and this can leave some isolated.

Medical transition is also an issue for young people with special health care needs and their families. While children's specialty hospitals and providers will see children until they reach age 21, other pediatricians will only see children until age 18. In either case, ultimately parents need to find adult providers for their special needs children, and this can be difficult because adult providers often have less experience working with special needs patients. Several parents shared that they have transitioned their children to their own providers; as one explained, *"My son will use my family medicine doctor—he has been coming to appointments with me since he was young. The doctors know him. We already go to the dentist. Our dentist was already treating people with autism; even eye doctors we go to the same everything."*

### *Respite and Long-Term Care*

Several interviewees shared that New Jersey has too few long-term care and respite beds for children with special healthcare needs. One provider shared, *"I have many families that are at a breaking point and there's no respite program for these patients."* While the number of long-term care beds has increased through the New Jersey Children's System of Care work, the demand currently exceeds the supply. One interviewee noted that these additional beds were intended to be short-term beds, but the average stay is two or more years. Parents reported that approval processes for respite and long-term care can be difficult, and the system does not always recognize that most parents with special needs children could benefit from respite services, not just those with children who have more significant health care needs. One interviewee echoed this and explained, *"I think that's a real important idea [that parents need a break every now and then]. It is difficult to figure out who pays for that."*

*"If you have money you can get respite care, long term care."*
– Key informant interviewee

### *Programs and Supports for Families*

Numerous organizations in New Jersey support parents/caregivers with advocacy and education including the SPAN Parent Advocacy Network, the New Jersey Council on Developmental Disabilities, Arc of New Jersey, Autism New Jersey, Mom2Mom, and the Boggs Center on Developmental Disabilities at Rutgers, among others. Parents reported that they have also benefitted from support groups for parents, but they must often travel to participate, which can be a barrier; since the pandemic, many of these have been virtual. While this works for some, especially parents who do not have childcare, other parents reported that they have missed the in-person interaction. For some however, in-person support groups are difficult because childcare is not provided. For others, language can be a barrier to participation because groups are offered in English. As one Spanish speaking survey respondent wrote: *"It is hard for me as a mother of a young adult to be able to help her more, especially not speaking English and not knowing the rights of a young woman with ADD. More support groups for mothers like me are needed in my language."* Parents and interviewees also reported that there are few supports for siblings of children with special needs and these can be very beneficial.

## **Barriers to Accessing Services**

### *Limited Promotion of Services*

While New Jersey has many resources to support children with special health care needs and their families, parents and interviewees reported that learning about them can be difficult. As described earlier, not knowing what types of services are available was a top challenge to accessing healthcare for community survey respondents. As one survey respondent noted: *"If you are not sure what to do, getting started in programs is not easy, and there aren't many helpful resources."* A Spanish-speaking survey respondent expressed a similar challenge saying, *"I would like my child to participate in these programs, but I don't know how to find out about this."* While 211 and organizations such as SPAN provide information about programs and services, parents mentioned that they most often learned about these programs from other parents. As one shared, *"Word of mouth is the best way to learn about resources."*

*"New Jersey has lots of resources, but I'm surprised at how few people know about them."* – Key informant interviewee

Perform Care, New Jersey's Children's System of Care Administrator, was frequently mentioned as a resource to families with children with disabilities. As one parent stated, however, *"Perform Care has been an asset – many people don't know it exists."* Another challenge with these services, a parent relayed, was that parents need to follow up on information about resources and *"Sometimes parents need it to be done by somebody. They need somebody to make the phone calls."* This can be particularly challenging for parents who do not speak English or who have other pressing issues in their lives. Culture also plays a role one person explained. In some cultures, an interviewee explained, it is an embarrassment to have a child with a disability, so these children sheltered, protected, hidden. Some cultures also have a prevailing belief that it is their responsibility to take care of their own and not to ask for assistance.

### *Limited Program Eligibility*

Community survey respondents also shared that some programs are only for "high functioning" children rather than for children with different levels of need such as children in wheelchairs or nonverbal children. Families of children who are multiply handicapped—those with severe physical limitations and/or very low cognition-- face substantial challenges. These children often require highly-structured supportive environments and may not be able to take advantage of opportunities available to other children—for example, work-based learning or some programs supporting physical activity or socialization. As one parent survey respondent wrote, *"Special needs programs are designed for able-bodied kids with neuro or behavioral issues."*

### *Location*

Parent focus group members and community survey respondents shared that it is difficult to find programs and services in their communities and they must travel long distances for their children to access them. This is one advantage of a virtual format for some of these programs. As one parent survey respondent wrote, *"[There are] support groups and it is very helpful, but in our town is not much. We always have to look for out of town."*

### *Cost*

Cost is also a factor as many programs charge a fee and thus are not equally accessible to all special needs children. Numerous parents/caregiver respondents to the community survey shared that cost prevented their children from being able to participate in some recreational and supportive programs. One survey respondent wrote, *"[Recreational programs] are too expensive for us. There's limited options and we just can't afford them. My kids would benefit from things like special needs martial arts and we can't afford [them]."*

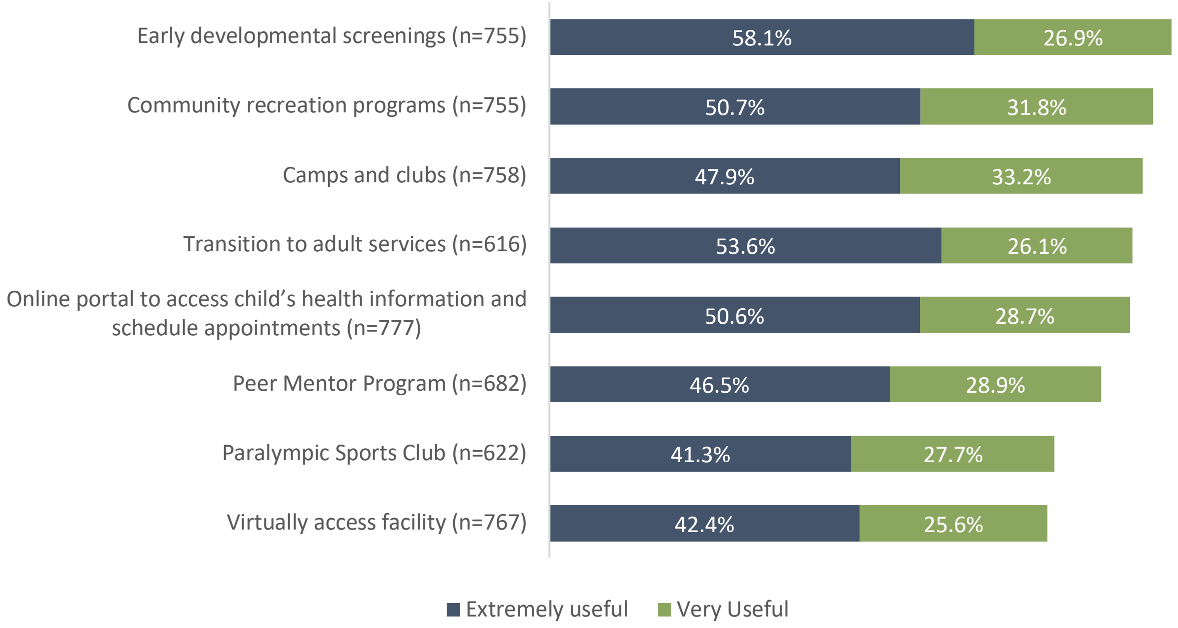
## Community Vision and Suggestions for the Future

Focus group and interview participants were asked for their suggestions for addressing identified needs and their vision for the future. Community survey respondents were asked about priority services. The following section summarizes and presents these recommendations for future consideration. Those most frequently discussed include early screening services, mental health services, programs for youth and families, and those that address social determinants of health. There were fewer suggestions in these discussions involving policy and systems change.

### Community Survey Results

Figure 43 shows community survey respondents perspectives on programs and services that would be extremely or very useful for children with special health care needs. Over 80% of respondents reported that early developmental screenings (85%), community recreation programs (82.5%), and camps and clubs (81.1%) would be extremely or very useful. In 2019, community survey respondents rated the same services as extremely useful or very useful, although in different order: transition to adult services; community recreation programs; early developmental screenings; and camps/clubs. As in 2022, fewer respondents rated virtual access and paralympic sports clubs as extremely or very useful for their children with special health care needs in 2019.

**Figure 43. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for Children with Special Health Care Needs, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Both parent/caregiver and other survey respondents identified the same five programs and services that would be most useful, in slightly different order of priority (Table 17). The highest proportion of parent/caregiver respondents (85.4%) rated early developmental screenings as extremely or very useful for children with special health care needs while the highest proportion of other respondents (86.6%) rated community recreation programs as extremely or very useful. In 2019, parent/caregiver community survey respondents rated the same services as extremely useful or very useful, but in a different order: transition to adult services; community recreation programs; early developmental screenings; and camps/clubs. In 2019, community survey respondents who were not parents or caregivers rated early developmental screenings as the programs most useful, followed by transition to adult services and community recreation programs.

**Table 17. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for Children with Special Health Care Needs, by Parents/Caregivers and Other Respondents, 2022**

| | Parents/Caregivers (n=697) | Other Respondents (n=60) |
|---|---|---|
| 1 | Early developmental screenings (85.4%) | Community recreation programs (86.6%) |
| 2 | Community recreation programs (82.2%) | Camps and clubs (86.9%) |
| 3 | Camps and clubs (80.7%) | Early developmental screenings (81.0%) |
| 4 | Transition to adult services (79.8%) | Transition to adult services (78.9%) |
| 5 | Online portal for health information (79.7%) | Online portal for health information (73.2%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Across all racial and demographic groups, the highest proportion of parent/caregiver respondents indicated that it would be extremely or very useful to have more early developmental screening (Table 18). Across all groups, community recreation programs were also identified as being extremely or very useful. A high proportion of Black parent/caregiver respondents and respondents who identified as other race or multiracial noted that peer mentoring programs would be extremely or very useful for their children with special health care needs; paralympic sports clubs were rated highly in terms of usefulness among Hispanic parent/caregiver respondents and those who identified as other race or multiracial. A high proportion of Asian and White parent/caregiver respondents indicated that an online portal for health information would be extremely or very useful.

**Table 18. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, by Race/Ethnicity 2022**

| | Black/ African American, NH (n=69) | Asian, NH (n=27) | White, NH (n=258) | Hispanic/ Latino(a) (n=209) | Other/ Multiracial (n=31) |
|---|---|---|---|---|---|
| 1 | Early developmental screenings (89.0%) | Early developmental screenings (88.5%) | Early developmental screenings (79.2%) | Early developmental screenings (91.5%) | Early developmental screenings (88.5%) |
| 2 | Peer mentor program (87.1%) | Community recreation programs (88.0%) | Community recreation programs (75.5%) | Community recreation programs (90.1%) | Peer mentor program (79.3%) |
| 3 | Community recreation programs (86.1%) | Transition to adult services (82.6%) | Online portal for health information (74.4%) | Camps and clubs (89.5%) | Paralympic sports club (75.0%) |
| 4 | Camps and clubs (85.5%) | Online portal for health information (80.0%) | Camps and clubs (73.3%) | Paralympic sports club (87.2%) | Transition to adult services (73.1%) |
| 5 | Transition to adult services (83.9%) | Camps and clubs (77.8%) | Transition to adult services (70.7%) | Online portal for health information (86.4%) | Community recreation programs (72.7%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Parent/caregiver respondents with private and with government insurance rated the same programs and services as most useful, with early development screenings and community recreation programs topping the list (Table 19).

**Table 19. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, by Insurance Status, 2022**

| | Private Insurance (n=244) | Government Insurance (n=361) |
|---|---|---|
| 1 | Early developmental screenings (84.7%) | Early developmental screenings (86.5%) |
| 2 | Community recreation programs (83.4%) | Community recreation programs (81.5%) |
| 3 | Transition to adult services (79.8%) | Camps and clubs (80.8%) |
| 4 | Camps and clubs (78.5%) | Online portal for health information (80.6%) |
| 5 | Online portal for health information (76.5%) | Transition to adult services (79.8%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Table 20 shows responses from parent/caregivers by age of children with special health care needs. Among parents of special needs children 18 and younger, the highest proportion of respondents rated early development screenings and community recreation programs as extremely or very useful. Over 90% of parents of youth older than 18 responded that programs and services to support transition to adult services would be extremely or very useful. A large proportion of parents of special needs children ages 10 to 18 saw peer mentoring programs as very valuable.

**Table 20. Percent of Parent/Caregiver Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, by Age of Child, 2022**

| | **Under 5 years (n=117)** | **5 -9 years (n=182)** | **10-14 years (n=153)** | **15-18 years (n=58)** | **Older than 18 years (n=61)** |
|---|---|---|---|---|---|
| **1** | Early developmental screenings (84.9%) | Early developmental screenings (86.3%) | Early developmental screenings (82.4%) | Community recreation programs (94.6%) | Transition to adult services (91.5%) |
| **2** | Community recreation programs (79.0%) | Community recreation programs (84.8%) | Community recreation programs (79.3%) | Early developmental screenings (91.2%) | Early developmental screenings (84.5%) |
| **3** | Online portal for health information (78.3%) | Camps and clubs (83.0%) | Camps and clubs (78.4%) | Transition to adult services (87.5%) | Community recreation programs (83.6%) |
| **4** | Camps and clubs (77.8%) | Online portal for health information (77.5%) | Online portal for health information (76.9%) | Camps and clubs (86.2%) | Camps and clubs (82.0%) |
| **5** | Transition to adult services (75.6%) | Transition to adult services (76.8%) | Peer mentor program (76.7%) | Peer mentor program (85.5%) | Online portal for health information (81.7%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

The community survey also asked respondents to rate programs and services as to whether they should be given low, medium, or high priority by facilities that serve children with special health care needs. Over three quarters of respondents rated social, emotional, and other mental health services and outpatient services as high priority (Figure 44). Nearly two-thirds of respondents rated transition to adult services and services and workshops for parents and caregivers as high priority. In 2019, the same top four programs and services were rated as highest priority by survey respondents. Among young adult respondents to the survey (n=19), the programs and services that were identified as those that would be most useful included an online portal (73.3%), camps and clubs (58.8%), mental health programs (52.9%), transportation services (52.9%), and outpatient services (52.9%).[18]

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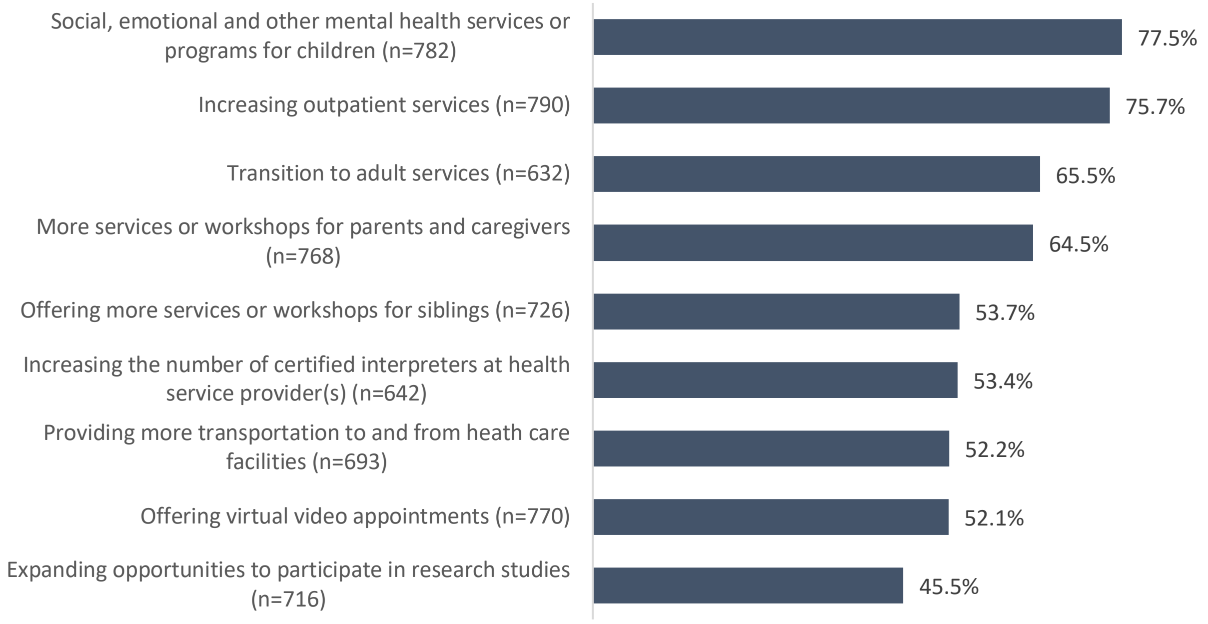
[18] The young adult component of the survey combined two questions from the adult survey, usefulness of potential programs and services and those that should be high priority.

**Figure 44. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

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, outpatient services, and transition to adult services as highest priority (Table 21). Other respondents were more likely than parent/caregiver respondents to rate transportation to and from healthcare services as high priority. In 2019, the same top four programs and services were rated as highest priority by parent/caregiver survey respondents: social, emotional, and other mental health services, outpatient services, transition to adult services, and services and workshops for parents and caregivers. In 2019, community survey respondents who were not parents or caregivers rated transition to adult services, mental health services, transportation services, and services and workshops for parents and caregivers as highest priority.

**Table 21. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers and Other Respondents, 2022**

| | Parents/Caregivers (n=725) | Other Respondents (n=59) |
|---|---|---|
| 1 | Social, emotional, and other mental health services (78.3%) | Social, emotional, and other mental health services (66.7%) |
| 2 | Outpatient services (76.5%) | Outpatient services (65.5%) |
| 3 | Transition to adult services (65.5%) | Transition to adult services (65.5%) |
| 4 | Workshops for parents and caregivers (64.8%) | Workshops for parents and caregivers (60.3%) |
| 5 | Services and workshops for siblings (54.6%) | Providing more transportation to and from healthcare facilities (59.3%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Suggested high priority programs and services were largely similar across racial and ethnic groups with social, emotional, and other mental health services and outpatient services identified as the top two priorities across all groups (Table 22). A higher proportion of Black and Hispanic/Latino parent/caregiver respondents identified transition to adult services and workshops for parents and caregivers as high priority, compared to Asian, White, and Other/Multiracial respondents. Interpreters at health facilities were identified as high priority by Asian and Hispanic respondents.

**Table 22. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Race/Ethnicity, 2022**

| | **Black/ African American, NH (n=75)** | **Asian, NH (n=26)** | **White, NH (n=277)** | **Hispanic/ Latino(a) (n=226)** | **Other/ Multiracial (n=33)** |
|---|---|---|---|---|---|
| **1** | Outpatient services (80.0%) | Social, emotional, and other mental health services (85.2%) | Social, emotional, and other mental health services (73.4%) | Social, emotional, and other mental health services (84.1%) | Social, emotional, and other mental health services (80.0%) |
| **2** | Social, emotional, and other mental health services (78.7%) | Outpatient services (80.8%) | Outpatient services (71.8%) | Outpatient services (78.3%) | Outpatient services (78.8%) |
| **3** | Transition to adult services (76.2%) | Workshops for parents and caregivers (59.3%) | Workshops for parents and caregivers (55.3%) | Transition to adult services (73.6%) | Workshops for parents and caregivers (67.7%) |
| **4** | Workshops for parents and caregivers (70.7%) | Transition to adult services (52.4%) | Transition to adult services (53.7%) | Workshops for parents and caregivers (72.2%) | Services and workshops for siblings (63.6%) |
| **5** | Providing more transportation to and from healthcare facilities (67.1%) | Increasing the number of certified interpreters at health care facilities (43.5%) | Offering virtual video appointments (49.8%) | Increasing the number of certified interpreters at health care facilities (66.3%) | Transition to adult services (58.3%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

While parent/caregiver respondents with private and public health insurance similarly prioritized increased mental health services and programs, outpatient services, transition to adult services, and workshops for parents and caregivers, a higher proportion of respondents with government insurance rated transportation services as high priority (Table 23).

**Table 23. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Insurance Status, 2022**

| | Private Insurance (n=259) | Government Insurance (n=403) |
|---|---|---|
| **1** | Social, emotional, and other mental health services (79.1%) | Social, emotional, and other mental health services (80.3%) |
| **2** | Outpatient services (77.8%) | Outpatient services (77.2%) |
| **3** | Transition to adult services (62.8%) | Workshops for parents and caregivers (70.5%) |
| **4** | Workshops for parents and caregivers (56.4%) | Transition to adult services (65.6%) |
| **5** | Offering virtual video appointments (49.4%) | Providing more transportation to and from healthcare facilities (61.8%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

Parents/caregiver survey respondents with children with special health care needs between the ages of under 5 and 18 identified the same two top priorities: outpatient services and mental health services (Table 24). Respondents with special needs children over 18 identified transition to adult services as highest priority. Workshops for parents and caregivers were identified as high priority by two-thirds of parent/caregiver respondents with children under 5 and between 5 and 9 years old; these same respondents also prioritized workshops and services for siblings of children with special health care needs.

**Table 24. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Age of Child, 2022**

| | Under 5 years (n=130) | 5 -9 years (n=189) | 10-14 years (n=173) | 15-18 years (n=62) | Older than 18 years (n=61) |
|---|---|---|---|---|---|
| 1 | Outpatient services (75.4%) | Social, emotional, and other mental health services (80.0%) | Social, emotional, and other mental health services (78.5%) | Outpatient services (83.9%) | Transition to adult services (86.2%) |
| 2 | Social, emotional, and other mental health services (74.6%) | Outpatient services (76.2%) | Outpatient services (72.8%) | Social, emotional, and other mental health services (77.1%) | Outpatient services (82.0%) |
| 3 | Workshops for parents and caregivers (67.2%) | Workshops for parents and caregivers (66.0%) | Transition to adult services (58.6%) | Transition to adult services (75.0%) | Social, emotional, and other mental health services (82.0%) |
| 4 | Transition to adult services (57.1%) | Services and workshops for siblings (59.8%) | Workshops for parents and caregivers (58.2%) | Offering virtual video appointments (66.1%) | Workshops for parents and caregivers (68.3%) |
| 5 | Services and workshops for siblings (55.1%) | Transition to adult services (59.7%) | Offering virtual video appointments (52.1%) | Providing more transportation to and from healthcare facilities (56.6%) | Offering virtual video appointments (62.1%) |

DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

## Expanding and Strengthening Healthcare Services

Focus group and interview participants were asked for their suggestions for their vision for the future and what services would be most helpful to see. The following section summarizes these recommendations from participants.

### *Expand Services for Early Diagnosis*

Given the connection between early diagnosis and care to better outcomes, participants and survey respondents stated that more early developmental screenings are needed. As described above, a high proportion of community survey respondents—across all groups—rated early developmental screenings as services that would be extremely or very useful. Similarly, interviewees noted that enhancing services for early diagnosis should be a priority. As one interviewee shared, "*There needs to be more around early diagnosis. I've heard the earlier somebody diagnosed, the better some of the outcomes. If they're not diagnosed until say seven or eight, they've missed out on an OT and PT and all of these things.*" Suggestions focused on expanding the number of providers able to conduct assessments as well as more flexibility in offering these appointments, such as during the evening or weekends. One interviewee recommended hiring and training more developmental-behavioral physicians who are adept at evaluating children and working with others, including school systems, to ensure appropriate services are provided.

### *Expand Subspeciality and Therapy Services*

Participants and survey respondents identified a need for there to be more providers in many areas of care for children with special health care needs. A high proportion of community survey respondents identified more outpatient services as high priority. Interviewees and community survey respondents through open-ended comments reported that children with special health care needs could benefit from more OT, PT, and speech therapy providers. Because transportation and work hours present barriers for some families to access services, participants also suggested that services be located closer to home and have evening and weekend hours. One survey respondent who works with special needs children wrote that what is needed is, *"Talk or play therapy, OT, PT, that is both in network, local, available without having to miss school and accepts insurance."* Expanding the array of services and programs offered at current outpatient locations was suggested by several parents participating in focus groups and responding to the community survey. One parent/caregiver respondent suggested increasing the length of time insurance covers therapeutic services.

### *Improve Competency of the Provider Workforce*

Numerous focus group members, interviewees, and survey respondents shared that more needs to be done to enhance the competency and sensitivity of the healthcare workforce to work with children and young adults with special healthcare needs. Parents suggested that this competency needs to involve listening more carefully to parents and respecting their input and knowledge. Suggestions included training of primary care providers and medical residents so that *"Primary care is disability-informed.*" Training for mental health providers and dentists was also suggested. One community survey respondent wrote, *"Treating anxiety or depression or even OCD in a child who is autistic requires a different strategy than it does for neurotypical kids. But few providers seem to understand this."*

Participants mentioned that specialty hospitals could play a lead role in this by training other providers. One interviewee suggested physician-to-physician mentoring that pairs physicians trained to work with special needs children with other providers to enhance their expertise. Several parents shared difficult experiences they had with front office and other staff in providers' office and suggested that training in how to work with, and treat, children with special health care needs and their families was needed office-wide.

### *Enhance and Expand Coordination/Case Management Services*

Participants saw a need for more case managers and social workers to help families learn what resources are available and get connected to them. One interviewee advocated for a more collaborative approach among providers, schools, and community-based organizations, with a goal of identifying needs and connecting families to organizations that address the social determinants of health. This person suggested that hospital staff could play an important role in coordinating across systems.

### *Enhance Use of Technology to Support Care*

While not a prominent theme in focus group discussions and interviews, parent/caregiver survey respondents advocated for greater use of technology to help them access health care for their children with special health care needs. While virtual healthcare visits will not work for all, a high proportion of respondents reported that they had used and were satisfied with telehealth and slightly over half reported that they were extremely likely or very likely to use telehealth to access care for their children with special health care needs in the future. Similarly, about half reported that offering virtual video appointments should be high priority. Close to three quarters of young adult survey respondents reported that an online portal to access health information would be very useful.

*Increase Interpretation Services*

A few interviewees stated that some families face language barriers to accessing care for their special needs children and suggested that health care facilities and other programs serving children with special health care needs and their families make information about services and programs available in multiple languages and ensure language access. A high proportion of Asian and Hispanic parent/caregiver survey respondents indicated that increasing the number of interpreters at health care facilities should be a high priority.

**Expanding Mental Health Services**

Concerns about the mental health of young people with special health care needs and the need for more programs to support them were prevalent throughout the community survey, in conversations with parents, and in interviews. As described earlier, a high proportion of survey respondents identified social, emotional, and other mental health services as "high priority." This was consistent across parents/caregivers from different racial/ethnic groups, who have different insurances, and who have children of different ages. Survey respondents as well as interviewees identified a need for more psychologists and psychiatrists for children with special health care needs as well as more board-certified behavioral analysts (BCBA). Increasing the number of mental health providers accepting Medicaid was also suggested. Parent/caregiver survey respondents and parent focus group members recommended expansion of therapies such as ABA, Cognitive Behavioral Therapy (CBT), and DIR®/play, as well as more group therapy programs. Several parent/caregiver survey respondents also expressed a need for mental health services that, as one person wrote, are "*specifically designated for neurodivergent kids to help them understand and accept their differences."* One person shared that there is a need for more in-home supports to mitigate crises with children, including better connection with schools and school services.

**Increasing Affordable and Accessible Programs for Children and Youth**

Community survey respondents, including young adults, overwhelmingly saw a need for more programming for children and youth with special health care needs. Parent focus group participants and interviewees likewise saw a need for this, noting that programming was cut back during the pandemic.

*Offer More Peer Social Groups*

A key theme in conversations with parents and in open-ended comments in the community survey was the value of social interaction with peers for children with special health care needs. Parents saw these groups as valuable in helping their children to share experiences with like peers and, as one parent stated, *"know they are not alone."* Peer groups, parents stated, give their children a sense of belonging, a place to share frustrations, and are a source for learning about how to navigate their disability. Parents and young adult survey respondents suggested more programs like these are needed. Some parents advocated for groups in which children engage with others with similar abilities: Deaf/Hard of Hearing, ADHD, epilepsy, non-verbal children. Several parents suggested a virtual format so this opportunity could reach more children and youth. Another suggested groups that included "typical" children saying, "*I think there needs to be education for typical kids and how to socialize with children with kids that are different*."

*Expand Recreation and Sports Programs*

Youth, young adults, and parents/caregivers shared the types of programs they saw children and youth with special needs enjoying and that they recommended be expanded:

- *Sports Programs:* Youth and parents alike suggested more sports programs, including swimming, karate and basketball. Key to this, one person shared, is collaboration with programs in the community such as, for example, YMCAs and town recreation departments.
- *Camps:* Parent/caregiver and young adult survey respondents noted that there are limited summer and day camp opportunities for children with special health care needs and they are often far away. They saw a need for more camps for children with special health care needs across all ages; several also suggested support for children's attendance at other camps. One parent suggested, *"A camp through the summer that focuses on social, emotional and mental health for children with special needs."* A few parents recommended more training for camp counselors in working with special needs children.
- *Arts Programs*: Art and music programs were mentioned by several community survey respondents as important. They reported that there were currently few opportunities in their communities. Some also suggested art therapy programs as programming to support mental health.

*Reduce Barriers to Participation in Programs*

Cost is a substantial barrier for many families, so parents advocated for lower cost and free programs for their special needs children. They also advocated for programs and services that are inclusive of children and youth with range of abilities, not just those who are higher functioning.

### Expanding Transition Services

The transition to adulthood and adult services is a substantial challenge for young people with special health care needs and their families. As described earlier, two-thirds of parent/caregiver survey respondents as well as two-thirds of other respondents identified transition to adult services as "high priority." About 86% of parents/caregivers with children 18 and older saw these services as high priority. Numerous suggestions were shared about areas for expansion and enhancement.

*Enhance Information to Parents about Transition Planning*

Lack of parent understanding about what will happen as their child ages out of pediatric and school systems is a strong concern. As one survey respondent wrote, *"Most parents lack the know-how in preparing their special needs patients for adulthood, so they need that guidance to help prepare them."* Numerous respondents mentioned need for assistance with guardianship and understanding and applying for programs available for adults with special needs like Supplemental Security Income (SSI), Department of Vocational Rehabilitation services (DVR), and Division of Developmental Disabilities (DDD) services. Parents need to understand the importance of planning far in advance and how to do so, interviewees and parents reported. Some parents may need additional support with this. Suggestions included workshops and presentations that walk parents through the steps that need to be considered, the processes and paperwork required, and answers questions. Hands-on support, such as from social workers and care coordinators, was suggested. Helping parents develop contingency plans was also suggested by one parent: *"Offer a Plan B when patient graduates and DVR flops, so they are not sitting at home doing nothing till age 21 and they are DDD eligible."*

*Enhance the Role of Pediatricians in Health Transition Planning*

Several participants suggested that, because of their role as trusted resources, pediatricians can start conversations earlier on with parents about their children's future plans and connect them to resources and support, ideally far in advance of when their children age out of children's services. Parents also advocated for greater involvement of pediatricians from specialty hospitals in helping parents find adult medical providers for their children. Parents shared that they often have to start over with new medical systems when their children turn 21, and this can be very challenging. As one parent survey respondent stated, *"Children have received their care all through their young years (at specialty hospitals) and I think [these hospitals] can help bridge the adult service system by having information available on the adult systems services and making that part of their routine."* This might mean having more staff who can navigate systems and providing training and support to physicians to interact and work with families.

### *Expand Work Opportunities and Job Supports*

A theme in many conversations about transition to adulthood for young people with special health care needs was the need for more supports for workforce development. Specific suggestions included:

- *Exposure to employment pathways*. Participants and survey respondents recommended expansion of opportunities for young people with special health care needs to learn about different careers, including better guidance about post-high school opportunities, career fairs, programs that provide exposure to different job settings, meaningful job sampling, and greater access to vocational training. One person suggested that there be more job opportunities that enable young people to work from home on their computers. Exposing young people to these opportunities sooner—in the middle school years—was also recommended.
- *Job supports*. Parents, young people, and those who work with children and youth with special health care needs suggested that job coaching and job support programs and services be expanded and include longer-term follow up and support to ensure that young people are set up for success in their chosen fields. One interviewee suggested that agencies that place employees and career search services should more actively reach out to and include job opportunities for individuals with special needs.
- *Volunteer opportunities*. Parents participating in the focus group reported that they would like more opportunities for their children to participate in volunteer opportunities. As one parent stated, *"Whatever we can do for our kids to feel productive is good."*
- *Life skills training*. While young people receive some life skills training in schools, survey respondents and parent focus groups advocated for more community-based programs. They suggested that young people with special health care needs learn about budgeting, grocery shopping, laundry, simple food preparation, and navigating transportation.
- *Transportation*. Several parents reported that there should be more transportation options for young adults with special needs commuting to and from work and education and support to help them navigate it.

### *Increase Socialization Programs for Young Adults*

As described earlier, parents in focus groups and in the community survey greatly value opportunities their children have to socialize with other children and youth, through school-based programs, sports, recreation programs, and peer groups. However, they reported, there are far fewer of these opportunities for young adults and many opportunities that do exist include adults of all ages. Parents advocated for more peer groups and recreational and other programs for their older children, with a focus on opportunities to socialize and share experiences. A few specifically mentioned the need for programs that are age specific (those in their 20's) to provide support to young people as they navigate the transition to adulthood. One parent suggested that those organizations providing programs for younger people with special health care needs consider having periodic "reunions" of past participants to enable them to socialize and to check in to make sure they are being supported.

### Expanding Supports for Families

Supporting families of children with special health care needs was a frequent topic of conversation in interviews and the parent focus group and was identified as "high priority" in the community survey. Suggestions included:

- *Parent Workshops*. Parents would like more opportunities for education, either in person or virtually. Suggested topics included housing, Medicaid, Social Security benefits, working with schools, and navigating transition to adulthood.
- *Support Groups*. Participants and survey respondents recommended more opportunities for families to connect to other families and discuss experiences and issues, especially ones that are more local. Support groups help parents know they are not alone and that it is OK to ask for help, as one person stated: *"I think it's the people who have gone through this before that help us get free of that burden that it is okay to ask for help."* Parents stated that flexibility in offering these programs—virtually and in-person, during the day and at night—was important to engaging families. Several parents noted that in-person programs should also offer childcare. One person suggested greater homogeneity within support groups with respect to the challenges parents are facing; as this person stated, *"Have parents in a group with parents who are in the same place, whose child has the same needs. It's hard for parents to hear about the challenges of another parent and have that not be their challenges at all."* A few parents pointed to the Family Faculty approach at CSH as one model for connecting families with advice and support.
- *Support for siblings.* Several parent focus group participants and survey respondents recommended more programs that support the siblings of children with special health care needs. They suggested family social events as well as support groups specifically for siblings.
- *Respite services.* Noting that family well-being sometimes requires a break, parents and caregivers suggested more residential care and respite services.

### Ensuring Information about Programs and Services Reaches Families

Parents/caregivers stressed the importance of programs close to home and noted that information about programs needs to reach families of all types of across New Jersey . They suggested that information about programs be available in multiple languages and be shared in multiple formats, including social media, email, television and radio, and flyers.

### Focusing on the Social Determinants of Health

#### *Provide Support for Transportation*

Lack of transportation was identified as a barrier to accessing health and other services for special needs children, especially in the community survey. Suggestions to address this included:

- *Expansion of Existing Transportation Services*. A few participants suggested expanding services like LogistiCare and Access Link which provide transportation for children with special health care needs. Because these programs are income-eligible, need for options for other families was also noted. Parents recommended more shuttles and van/bus services, including with accessibility support. They also suggested hospital-provided transportation for medical appointments, especially for lower income families.
- *Reimbursement/Vouchers for Transportation*. Another mechanism for transportation support suggested by participants is transportation reimbursement or vouchers for use with public transportation and car services such as Uber and Lyft.

_Ensure Families are Connected to Programs that Address SDOH_

Several interviewees mentioned the need for continued partnership between hospitals and community organizations to ensure that families' other needs that affect health care addressed. They recommended continued connection to programs such as food and legal services through partnerships between CSH and community organizations. Making sure families are aware of services is also important, such as through roles such as social workers in hospitals and providers' offices and ensuring providers know about these services is another important aspect. One interviewee advocated for a more collaborative approach among providers, schools, community-based organizations, with a goal of identifying needs and connecting families to organizations that address social determinants of health.

**Advocacy for Systems Change**

A couple of parent focus group members shared that they would like to see more training to help parents/caregivers understand and be advocates for their children as they work with education, health, and benefits systems. At the same time, interviewees also suggested that CSH could play a greater role and have more of a presence statewide, statewide conversations about children's needs, such as through participation in the New Jersey Children's System of Care, the ARC of New Jersey, and the developmental disability legislative caucus. One person also suggested more engagement of families, and use of the FAC and Family Faculty at CSH: *"I think they should be at the table sharing what their successes are and what their challenges are so that we can hear directly and inform policymakers of those of those challenges."* Improving payment systems was seen as an important systemic priority.

## Key Themes and Conclusions

Through a review of the secondary social, economic, and epidemiological data; a community survey; and discussions with parents, young people with special health care needs, and stakeholders, this assessment report examines the current health status of special needs children in New Jersey during an unprecedented time given the COVID-19 pandemic. Several overarching themes emerged from this synthesis:

- ***New Jersey has many assets for families with children with special health care needs and their families, yet there are barriers to accessing these***. Compared to other states, New Jersey has many resources to support children with special health care needs and their families, including specialty hospitals and other health care services, school- and community-based programs that support education and social development, and statewide organizations that advocate and support parents and caregivers. Assessment participants noted that lack of awareness of existing programs and services is a barrier to access. Families with special needs children seeking health and mental health services additionally face challenges such as too few providers, long wait times for appointments, lack of evening and weekend hours, limits on insurance coverage, and cost. Particularly challenging are finding therapists, mental health providers, and subspecialists. Limited provider experience working with children and youth with special health care 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 narrow eligibility, and may be costly. Overall, assessment participants perceived limited programs and services to support young people with special needs as they transition to adulthood.

- ***The COVID-19 pandemic and current economic challenges have had substantial impact on the lives and the physical and mental health of children with special health care needs and their families.*** The COVID-19 pandemic has affected all sectors of life, including financial and mental well-being, education, access to healthcare, and food security. Families were isolated and disconnected from services, especially early in the pandemic, and 24/7 caregiving created additional stress for many families of special needs children. In addition to educational loss, children with disabilities were not able to access services they received in school at home during the height of the pandemic which has negatively affected student progress.

- ***Increasing access to key 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. Therapies located closer to home, through satellite locations, were seen as important. Participants also cited a need for more mental health providers such as psychiatrists and psychologists and those with experience in ABA, CBT, and DIR®/play therapies. Given the importance of early assessment to ensure children with special health care needs are connected to needed services, expanding the workforce of professionals able to conduct these assessments was also suggested. Enhancing the competency of the healthcare workforce to work with children and young adults with special healthcare needs and their families is also needed. Telehealth is one option to address some of these constraints but does not work for all patients.

- ***Opportunities exist to expand social and recreational programs for children with special health care needs, and support for their parents, caregivers, and siblings.*** Assessment participants frequently requested more programs, such as sports, arts, and recreation and camps, and opportunities for children and youth with special health care needs to socialize with their peers. Many also noted that parents/caregivers and siblings of children with special health care needs could benefit from additional educational and emotional support, including workshops and support groups, and from respite care. Addressing barriers such as location and cost is also important.

- ***Participants see a need for more transition programs***. Transition to adulthood is an overwhelming time for parents with special needs children and requires planning and support. Assessment participants suggested more information to parents about transition planning and support to undertake this and a greater role of specialty pediatricians in supporting the transition from pediatric to adult health care systems. For young people, they suggested expanded work opportunities and job support through exposure to employment pathways and job supports, volunteer opportunities, life skills training, socialization/peer programs, and support for transportation.

- ***Consideration should be given to transportation support and continued connection to services that address the social determinants of health***. Lack of transportation was identified as a barrier to accessing health and other services for special needs children, especially in the community survey. 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. Building on community-hospital partnerships on- and off-site to address the social determinants of health including food insecurity and legal concerns was also suggested. Ensuring information about these programs and services are accessible to all families is essential.

## Prioritization Process and Priorities Selected for Planning

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

### Criteria for Prioritization

A set of criteria were used to determine the priority issues for action. The RWJBH Systemwide CHNA Steering Committee put forth the following criteria to guide prioritization processes across the RWJBH system.

*Prioritization Criteria*

- **Burden**: How much does this issue affect health in the community?
- **Equity**: Will addressing this issue substantially benefit those most in need?
- **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**: Can we take steps to address this issue, given the current infrastructure, capacity, and political will?
- **Collaboration/Critical Mass**: Are 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.

*Step 1: Input from Community Members and Stakeholders via Primary Data Collection*

During each step of the primary data collection phase of the CHNA, assessment participants were asked for input. Key informant interviewees and focus group participants were asked about the most pressing concerns in their communities and what programs, services, policies or initiatives were needed to address them (see Key Informant Interview and Focus Group Guides in the Appendices). Community survey respondents were also asked to identify programs and services of highest priority for future action, described in the Community Vision and Suggestions for the Future section of the CHNA 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, nine initial issue areas were identified for CSH:

- Educational access and special education needs
- Financial insecurity
- Food insecurity
- Transportation
- Overweight/obesity
- Mental health and social emotional development
- Access to health care services
- Access to transition services
- Access to other services (support groups, recreation, camps and clubs)

*Step 2: Data Presentation Meeting*

On November 1, 2022, a 90-minute virtual community meeting was held with the CSH CHNA Advisory Committee as well as additional community members who were interviewed as part of this CHNA so attendees could hear data highlights and discuss them. During the virtual prioritization meeting on Zoom, attendees heard a brief data presentation on the key findings from the CHNA, including nine priority areas that arose from data analysis, and were invited to reflect on and discuss the data and offer their perspectives and feedback on the various issues.

*Step 3: Data Presentation Meeting*

After the meeting, attendees as well as CHNA Advisory Committee members who were not able to attend the meeting were sent a copy of the PowerPoint data slides that were shared at the meeting. They were also sent a follow up survey asking them to vote for up to four of the nine priorities identified from the data and based on the specific prioritization criteria (Burden, Equity, Impact, Systems Change, Feasibility, Collaboration/Critical Mass, and Significance to Community). A total of 13 individuals completed the survey.

Voting ranked the following issues as top priorities, with mental health and social emotional development receiving the highest percentage of responses.

| | Percentage | Vote #s |
|---|---|---|
| Mental health and social emotional development | 100% | 13/13 |
| Access to transition services | 69% | 9/13 |
| Access to health care services | 62% | 8/13 |
| Food insecurity | 62% | 8/13 |
| Education | 31% | 4/13 |
| Access to other services (support groups, recreation, camps and clubs) | 31% | 4/13 |
| Financial insecurity | 23% | 3/13 |
| Transportation | 23% | 3/13 |
| Overweight/obesity | 0 | 0/13 |

Key priority areas for the hospital will include mental health and social emotional development, access to transition services, access to health care services, food insecurity, and access to other services (support groups, recreation, camps and clubs) as it also considers its existing expertise, capacity, and experience during the development of its implementation plan in 2023.

# APPENDICES

## Appendix A- Organizations Engaged Through Key Informant Interviews

BOGGS Center on Developmental Disabilities

City of Elizabeth Health Department

Community Food Bank of New Jersey

Department of Psychiatry, Children’s Specialized Hospital

Fair Haven Public School District

Legal Services of New Jersey

Monmouth Medical Center

New Jersey Council on Developmental Disabilities

Statewide Parent Advocacy Network (SPAN)

## Appendix B- Key Informant Interview Guide

Goals of the interviews

- To determine key informants' 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

**[NOTE: QUESTIONS FOR THE INTERVIEW GUIDE ARE INTENDED TO SERVE AS A GUIDE, NOT A SCRIPT.]**

### BACKGROUND (5 minutes)

- Hi, my name is __________ and I am with Health Resources in Action, a non-profit public health organization located in Boston. 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.

- The goal of the community needs assessment is to gain a greater understanding of children with special healthcare needs in New Jersey, and how health needs are currently being addressed. As part of this process, we are conducting interviews with a wide range of people including health and mental health providers and staff from community organizations, public health and advocacy groups. We are interested in hearing people's feedback on the strengths and needs of the community and suggestions for Children's Specialized role.

- We are conducting several interviews and will also be conducting focus groups with parents and caregivers of Children's Specialized patients and with transition-age youth with special health care needs. We greatly appreciate your feedback, insight, and honesty.

- Our interview will last about 45-60 minutes. After our data collection, we write a summary report of the general themes that have emerged during the discussions. We will not include any names or identifying information in that report. All names and responses will remain confidential.

- 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 <u>day-to-day</u> concerns for children with special health care needs and their families in New Jersey?** [PROBE ON SDOH: Transportation, Housing, Employment, Access to Food, etc.] [PROBE ON SPECIFIC POPULATIONS: Transition-age youth]
    a. How have these changed as a result of COVID-19?

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 <u>health</u> concerns for children with special health care needs and their families?** [PROBE ON SPECIFIC POPULATIONS: Transition-age youth]
    a. How have these changed during the COVID-19 pandemic?

    [IF NOT BROUGHT UP, PROBE: transition services; developmental and behavioral services; speech and occupational therapy, long-term care]

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 health care needs and their families that are not so pressing currently, but potentially could be?**

## PROGRAM / SERVICE ENVIRONMENT (20 minutes)

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?**
    a. What do you think needs to be done to address these gaps?
    b. 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?
    c. 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 Guides

### PARENT/CAREGIVER FOCUS GROUP

Goals of the focus group

- To determine participants' 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 needs more effectively
- To explore the role Children's Specialized can play in addressing needs

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

- Hi, thank you for taking the time to speak with us today. My name is XX, and I am joined by my colleague, XX, who will take notes during our conversation. We are with Health Resources in Action, a public health organization located in Boston, Massachusetts. Children's Specialized hired us to support their community health needs assessment.

- Donna shared some information about our project ahead of time, but let me just briefly recap. A community health needs assessment is a report that shares information with the hospital about the community it serves—who is in that community, their assets and needs, and how the hospital can help. The hospital uses this assessment to develop an action plan to better serve the community.

- This conversation is an important part of that process. We are hoping to learn about your experiences meeting the needs of your children—what's working, what are the barriers, where more services and programs are needed. We will be having a similar conversation with youth; we are also conducting a community survey and interviewing people in health care, the disabilities community, education, and community-based organizations. We greatly appreciate your feedback, insight, and honesty.

- After our data collection, we will write a summary report of the general themes that have emerged during the discussions. We will not include any names or identifying information in that report. All names and responses will remain confidential.

- Our conversation will last about 60 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.

- [If many are present] We are a large group and I will work hard to make sure everyone who wants to speak is able to. I invite you to raise your hand if someone else is speaking and you would like jump in. I also invite you to use the chat function to share your thoughts. I'd also request that we all monitor our own airtime and give others the opportunity to speak.

- Do you have any questions before we begin?

1. **Let's first spend a little time getting to know one another. Let's go around and introduce ourselves. Please tell me: 1) Your first name; 2) where you live; 3) something about yourself you'd like to share– such as [# KIDS, FUN, TV SHOW].**

## CONCERNS AND BARRIERS (20 minutes)

2. **I'd like to start out hearing about what is working well for you in terms of supporting the health and well-being of your child/children?**
    - What has facilitated this?

3. **I am wondering if you could share with me some of the biggest day-to-day concerns you and other parents have relative to supporting your children with special health care needs?** [PROBE ON SDOH: Transportation, Housing, Employment, Access to Food, etc.]
    - How have these changed since the COVID-19 pandemic?
    - Where do you go to get support with these concerns?

4. **Let's move onto health. What are the most pressing health care concerns you have about your children with special health care needs?** [PROBE ON: transition services, access to healthcare, developmental and behavioral services, speech and occupational therapy, long-term care]
    i. How have these changed since the COVID-19 pandemic?

## PROGRAM/SERVICE ENVIRONMENT (30 minutes)

5. **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?** [beyond services and programs, PROBE ON: policies, advocacy, coalitions, larger initiatives]

6. **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?**
    d. In your opinion, how effective have these been at addressing these issues? Why?

7. **What programs, services, policies or initiatives are currently not available for children with special healthcare needs and their families that you think should be?**
    e. What do you think needs to be done to address these gaps?

8. **As you know, this community health needs assessment is for Children's Specialized Hospital. We have talked about many gaps [recap]. Do you see a role for Children's Specialized in addressing these gaps?**
    f. What organizations or individuals might Children's Specialized partner with on this?

### YOUTH FOCUS GROUP

Goals of the focus group

- To identify the perceived strengths and needs of transition-age youth with special healthcare needs
- To understand youths' perceptions of CSH's role in the community
- To explore the role CSH can play in addressing the needs of youth with special health care needs

## BACKGROUND AND INTRODUCTIONS (10-15 minutes)

- Hi everyone! 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, an organization located in Boston, Massachusetts.

- We are here to help Children's Specialized Hospital better understand the needs of the people in the community and of those who go to the hospital for healthcare. So that we can give the hospital a clear picture of the needs of the whole community, we are having conversations, like this one, with a lot of different people.

- We're going to be having a focus group today. Has anyone here been part of a focus group before? A focus group is basically a group conversation with some guiding questions. You are here because we want to hear your opinions. I want everyone to know there are <u>no right or wrong answers</u> during our discussion. We want to know your opinions, and those opinions might be different from person to person. This is fine. Please feel free to share your opinions, both positive and negative.

- This discussion will last about 60 minutes. Please turn on your video, if possible, so that we can all see each other speaking.

- We will be talking with a lot of different groups of people this month, like parents, doctors and other hospital staff. After all of the conversations are done, we will be writing a report of the general opinions that come up. In that report, we might provide some general information on what we talk about today, but will not include any names or identifying information. What you say is confidential, and no one will be able to know who said which comments. XX will be taking notes during our conversation but nothing you say here will be connected to your name.

- Does everyone feel comfortable participating in this conversation today? Participation is voluntary, and if I ask a question that you don't feel comfortable answering it's okay, just tell me and we can move on to the next questions.

- Do you have any questions before we begin?

1. **Let's first spend a little time getting to know one another.  Let's go around and introduce ourselves. Please tell me: 1) Your first name; 2) your age; and 3) something about yourself you'd like to share– such as your favorite movie or an activity you like to do for fun.**

2. **Let's start by talking about the things in your community that support you as a young person. What types of organizations, programs, and people help you to be successful?** [PROBE: schools, groups like Friday Night Fever, sports and recreational programs, education programs, job/career/community experience programs]

3. **What do you like about these?**

4. **What don't you like about these?**

5. **Thank you so much for telling me about [recap]. Now I'd like to hear about what is missing. What do you wish were available to you?** [PROBE: sports programs, support with post-secondary education, career/job/community experiences, recreational programs, youth coalition/self-advocacy]

6. **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 could Children’s Specialized Hospital do?

**Appendix D- Community Survey**

**CHILDREN'S SPECIALIZED HOSPITAL**
**2022 COMMUNITY HEALTH NEEDS ASSESSMENT SURVEY**
**[ONLINE SURVEY]**

**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 health care needs in your community.

The survey will take approximately 10 minutes to complete. All responses are kept completely anonymous.

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 Amazon, Applebee's, and AMC theaters, among others. Two winners will be chosen.

Let's shape the future of health care 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 health care needs** (for example, those with developmental disorders, autism, cerebral palsy, ADHD, head injuries, etc.)

2. Are you a **parent or caregiver** of at least one child with special health care needs?
Yes **[PN: SKIP TO Q3]**
No

**[PN: ASK 2A IF "NO" TO Q2. SINGLE RESPONSE.]**
2a. Are you a young adult with special health care needs?
- ☐ Yes **[PN: SKIP TO Q25]**
- ☐ No

**[PN: ASK 2B IF "NO" TO Q2A. SINGLE RESPONSE.]**

2b. How would you best describe your relationship to a child with special health care needs?
- ☐ A family member (e.g., sibling, grandparent, aunt/uncle, etc.)
- ☐ A non-family member (e.g., friend, neighbor, etc.)
- ☐ Work with children that have special health care 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, or work with any children having special health care 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 with special health care 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 health care 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 in **<u>your community</u>** for children with special health care needs and their families.

   How easy or hard is it to access each of the following in **<u>your community</u>**?

| | Very Easy | Easy | Not Easy or Hard | Hard | Very Hard | Don’t know |
|---|---|---|---|---|---|---|
| Primary care for children with special health care needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Specialty care for children with special health care needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Dental care for children with special health care needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Behavioral/mental health care for children with special health care needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Recreational programs for children with special health care needs (e.g., camps, concerts, social events, art programs, sports programs, etc.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Educational programs for children with special health care needs (e.g., preschool, special education programs, K–12 education, etc.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Support groups for **<u>children</u>** with special health care needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| | Very Easy | Easy | Not Easy or Hard | Hard | Very Hard | Don’t know |
|---|---|---|---|---|---|---|
| Support groups for **<u>parents/caregivers/siblings</u>** of children with special health care needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Transition to adult services (e.g., job pathways/connections to adult services, etc.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**[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]** in **<u>your community</u>**.
What **[PN: INSERT ATTRIBUTE]** would you like to be more accessible in your community?

| | |
|---|---|
| Recreational programs for children with special health care needs | **[PN: INSERT TEXT BOX]** |
| Educational programs for children with special health care needs | **[PN: INSERT TEXT BOX]** |

## BARRIERS TO CARE (Continued)

**[PN: IF “PARENT/CAREGIVER” USE 6A QUESTION WORDING. ALL OTHERS USE 6B QUESTION WORDING. ALLOW MULTIPLE RESPONSES.]**

6a. Over the last few years, which, if any, of the following issues made it difficult for you to access health care for your child with special health care needs?

6b. In your opinion, which, if any, of the following issues do you feel make it more difficult for children with special health care needs to get the health care that they need?

*(Select all that apply.)*

☐ Lack of transportation

☐ Have no regular source of health care/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) was not eligible for services

☐ Language problems (e.g., difficulty communicating with doctor or office staff)

☐ Discrimination/unfriendliness of doctor or office staff

☐ Not knowing what type of services are available

☐ No available provider 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

☐ Ability to schedule an appointment quickly/have to wait too long to get an appointment (days/weeks/months)

☐ 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]**

## ABOUT COMMUNITY

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

7. How useful would it be if those facilities offered the following programs/services to children with special health care needs and their families?

| | Extremely Useful | Very Useful | Somewhat Useful | Not very Useful | Not Useful at All | Don't Know |
|---|---|---|---|---|---|---|
| Camps and clubs (e.g., recreational overnight and day camps/clubs for children based on their special need) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Community recreation programs (e.g., martial arts program, aquatic programs, etc.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Paralympic Sports Club | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Peer Mentor Program | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Early developmental screenings | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| A private online portal for families to access child's health information and schedule appointments | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Virtually access facility (e.g., through Skype or FaceTime) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Transition to adult services (e.g., job pathways/connections to adult services, etc.) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

## ABOUT COMMUNITY (Continued)

8. Again, think about facilities that serve children with special health care needs.

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

| | **[PN: RANDOMIZE]** | Low Priority | Medium Priority | High Priority | Don't know |
|---|---|---|---|---|---|
| 1. | Increasing the outpatient services (e.g., physical therapy, support groups, etc.) that are close by and easy to get to | ☐ | ☐ | ☐ | ☐ |
| 2. | Providing more transportation to and from the facility currently receiving heath care services | ☐ | ☐ | ☐ | ☐ |
| 3. | Offering virtual video appointments ("telemedicine") so that if there is a wait list for an in-person appointment, child(ren) could be seen sooner through a video appointment that takes place at home (i.e., do not have to travel to see a provider) | ☐ | ☐ | ☐ | ☐ |
| 4. | Increasing the number of certified interpreters at health service provider(s) | ☐ | ☐ | ☐ | ☐ |
| 5. | Expanding opportunities for children and their families to participate in research studies | ☐ | ☐ | ☐ | ☐ |
| 6. | Offering more programs or services that focus on social, emotional and other mental health issues for ***children with special health care needs*** | ☐ | ☐ | ☐ | ☐ |
| 7. | Offering more services or workshops for ***parents and caregivers*** of children with special health care needs (e.g., support groups, classes, etc.) | ☐ | ☐ | ☐ | ☐ |
| 8. | Offering more services or workshops for ***siblings*** of children with special health care needs (e.g., support groups, classes, etc.) | ☐ | ☐ | ☐ | ☐ |
| 9. | Transition to adult services (e.g., job pathways/connections to adult services, etc.) | ☐ | ☐ | ☐ | ☐ |
| 10. | Other resource (Please specify): **[PN: INSERT TEXT BOX]** | ☐ | ☐ | ☐ | ☐ |

**[PN: ASK 8A IF Q8-2 IS "MEDIUM OR HIGH PRIORITY"]**
8a. You indicated that priority should be given to providing more transportation to and from healthcare services.

Use the space below to specify what types of services and/or programs you would like to see offered.

**[PN: INSERT TEXT BOX]**
**[PN: ASK 8B IF Q8-6 IS "MEDIUM OR HIGH PRIORITY"]**

8b. 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 with special health care needs.

Use the space below to specify what types of services and/or programs you would like to see offered.

**[PN: INSERT TEXT BOX]**

**[PN: ASK 8C IF Q8-9 IS "MEDIUM OR HIGH PRIORITY"]**

8c. You indicated that priority should be given to offering more services that support transition to adult services for children with special health care needs.

Use the space below to specify what types of services and/or programs you would like to see offered.

**[PN: INSERT TEXT BOX]**

## IMPACT OF COVID-19

**THESE QUESTIONS ONLY FOR PARENT/CAREGIVER. DO NOT INCLUDE FOR THOSE WHO WORK WITH CHILDREN WITH SPECIAL HEALTH CARE NEEDS.**

The questions in this section are focused on community needs specifically related to COVID-19.

9. Have you or anyone in your immediate family lost employment due to COVID-19?
   - ☐ Yes
   - ☐ No

10. Have you or anyone in your immediate family lost housing due to COVID-19?
    - ☐ Yes
    - ☐ No

11. Below is a list of areas in which some people are experiencing difficulty as a result of COVID-19. Since COVID-19 started, has your family or your child with special health care needs experienced any difficulty with:
*(Select all that apply.)*

- ☐ Maintaining good physical health
- ☐ Maintaining a good mental state
- ☐ Maintaining good dental health
- ☐ Access to health care professionals
- ☐ Access dental care professionals
- ☐ Getting in-home care service
- ☐ Access to social services
- ☐ Access to childcare
- ☐ Access to healthy food
- ☐ Affording housing costs
- ☐ Getting essential supplies for daily living (i.e., toilet paper, cleaning supplies, personal care products, etc.)
- ☐ Managing schooling at home for children
- ☐ Taking care of a child with special health care needs
- ☐ Access to transportation
- ☐ Experiencing overall financial hardship
- ☐ Feeling lonely or isolated from others
- ☐ Understanding how to get the COVID vaccine

## USE OF TELEHEALTH

**THESE QUESTIONS ONLY FOR PARENT/CAREGIVER. DO NOT INCLUDE FOR THOSE WHO WORK WITH CHILDREN WITH SPECIAL HEALTH CARE NEEDS.**

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

12a. Have you accessed medical care virtually for your child with special health care needs, for example, through FaceTime, Skype or another virtual platform? How satisfied were you with the experience using this type of technology?

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

12b. If needed and you were able to access medical care virtually for your child with special health care needs, for example, through FaceTime or Skype or another virtual platform, how likely would you be to use this type of technology?

- ☐ Extremely likely
- ☐ Very likely
- ☐ Somewhat likely
- ☐ Not very likely
- ☐ No, not interested in using

## 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.**

**[PN: ALLOW MULTIPLE RESPONSES]**

14. How would you describe your race/ethnicity?

- ☐ African American/Black
- ☐ American Indian/Alaskan Native
- ☐ Asian
- ☐ Caucasian/White
- ☐ Hispanic/Latino(a)
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Other (Please specify: **[PN: INSERT TEXT BOX])**
- ☐ Prefer not to answer **[PN: SINGLE RESPONSE]**

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

- ☐ English
- ☐ Spanish
- ☐ Arabic
- ☐ Chinese
- ☐ Hindi

☐ Portuguese
☐ Other (please specify): **[PN: INSERT TEXT BOX]**
☐ Prefer not to answer

**[PN: ASK Q16 IF "PARENT/CAREGIVER". ALLOW MULTIPLE RESPONSES]**

16. 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 Q17 IF Q2A "Work with children that have special health care needs." SINGLE RESPONSE.]**

17. What type of organization do you work for?

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

**PN: ASK Q18 IF Q2A "Work with children that have special health care needs." SINGLE RESPONSE.]**

18. 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 Q19 IF "PARENT/CAREGIVER". ALLOW MULTIPLE RESPONSES]**

19. Please indicate the age of your child(ren) with special health care 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

## DEMOGRAPHICS (Continued)

20. Please indicate your age and gender identity.

**Age:**
☐ Younger than 18 years of age
☐ 18-21 years of age
☐ 22-24 years of age
☐ 25-34 years of age
☐ 35-44 years of age
☐ 45-54 years of age
☐ 55-64 years of age
☐ 65-74 years of age
☐ 75 years of age or older
☐ Prefer not to answer

**Gender identity:**
☐ Male
☐ Female
☐ Transgender
☐ Other
☐ Prefer not to answer

21. What is your highest level of education you have completed?
( ) Less than high school
( ) Some high school
( ) High school graduate or GED
( ) Some college
( ) Associate or technical degree/certification
( ) College graduate
( ) Post graduate or professional degree
( ) Prefer not to answer

22. Which of the following best describes your current employment status?
**[PN: ALLOW MULTIPLE RESPONSES.]**
( ) Employed full-time
( ) Employed part-time
( ) Student
( ) Homemaker
( ) Disabled
( ) Retired
( ) Unemployed **[PN: SINGLE RESPONSE]**
( ) Prefer not to answer **[PN: SINGLE RESPONSE]**

23. Approximately what is your entire household income before taxes?
( ) Under $25,000
( ) $25,000 - $50,000

( ) $50,001 - $75,000
( ) $75,001 - $100,000
( ) $100,001 - $125,000
( ) $125,001 - $150,000
( ) $150,001 - $200,000
( ) Over $200,000
( ) Prefer not to answer

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.***

## YOUNG ADULT SURVEY QUESTIONS

25. Please think about the different types of services and programs that are available in **<u>your community</u>** for you and other young people with special health care needs.

How easy or hard is it to access each of the following in **<u>your community</u>**?

| | Easy | Not Easy or Hard | Hard | Don't know |
|---|---|---|---|---|
| Primary care | ☐ | ☐ | ☐ | ☐ |
| Specialty care | ☐ | ☐ | ☐ | ☐ |
| Dental care | ☐ | ☐ | ☐ | ☐ |
| Behavioral/mental health care | ☐ | ☐ | ☐ | ☐ |
| Recreational programs (e.g., camps, concerts, social events, art programs, sports programs, etc.) | ☐ | ☐ | ☐ | ☐ |
| Educational programs | ☐ | ☐ | ☐ | ☐ |
| Support groups | ☐ | ☐ | ☐ | ☐ |
| Transportation services | ☐ | ☐ | ☐ | ☐ |
| Transition to adult services (e.g., job pathways/connections to adult services, etc.) | ☐ | ☐ | ☐ | ☐ |

If you have any comments on your answers above, please type them here:

26. How useful would it be to you and other young people with special healthcare needs to have the following programs/services?

| | Very Useful | Somewhat Useful | Not at all Useful | Don’t Know |
|---|---|---|---|---|
| Camps and clubs (e.g., recreational overnight and day camps/clubs) | ☐ | ☐ | ☐ | ☐ |
| Community recreation programs (e.g., martial arts program, aquatic programs, etc.) | ☐ | ☐ | ☐ | ☐ |
| Paralympic Sports Club | ☐ | ☐ | ☐ | ☐ |
| Peer Mentor Program | ☐ | ☐ | ☐ | ☐ |
| A private online portal to access health information and schedule appointments | ☐ | ☐ | ☐ | ☐ |
| Virtual video appointments (“telemedicine”) (e.g., through Skype or FaceTime) | ☐ | ☐ | ☐ | ☐ |
| Transportation to and from health care facilities | ☐ | ☐ | ☐ | ☐ |
| Transition to adult services (e.g., job pathways/connections to adult services, etc.) | ☐ | ☐ | ☐ | ☐ |
| Social, emotional and mental health programs | ☐ | ☐ | ☐ | ☐ |
| Outpatient services (e.g., physical therapy, support groups, etc.) that are close by and easy to get to | ☐ | ☐ | ☐ | ☐ |

27. What other programs or services would be helpful to you and other young people with special healthcare needs?

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

**[PN: ALLOW MULTIPLE RESPONSES]**

28. How would you describe your race/ethnicity?
    - ☐ African American/Black
    - ☐ American Indian/Alaskan Native
    - ☐ Asian
    - ☐ Caucasian/White
    - ☐ Hispanic/Latino(a)
    - ☐ Native Hawaiian or other Pacific Islander
    - ☐ Other (Please specify: **[PN: INSERT TEXT BOX]**)
    - ☐ Prefer not to answer **[PN: SINGLE RESPONSE]**

29. Please indicate your age and gender identity.

    **Age:**
    - ☐ Younger than 18 years of age
    - ☐ 18-21 years of age
    - ☐ 22-24 years of age
    - ☐ 25-34 years of age

☐ 35-44 years of age
☐ 45-54 years of age
☐ 55-64 years of age
☐ 65-74 years of age
☐ 75 years of age or older
☐ Prefer not to answer

**Gender identity:**
☐ Male
☐ Female
☐ Transgender
☐ Other
☐ Prefer not to answer

30. 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]**

## RAFFLE INFORMATION

**[PN: LINK TO GATHER RAFFLE INFO:]**
To enter the drawing, please enter your information below.

**Children's Specialized Hospital** will randomly select the winners. Winners will be drawn in mid-summer 2022 and notified via email.

Your name will not be linked to your survey responses.

Name: **[PN: INSERT FIELD]**
Email address: **[PN: INSERT FIELD]**

---

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

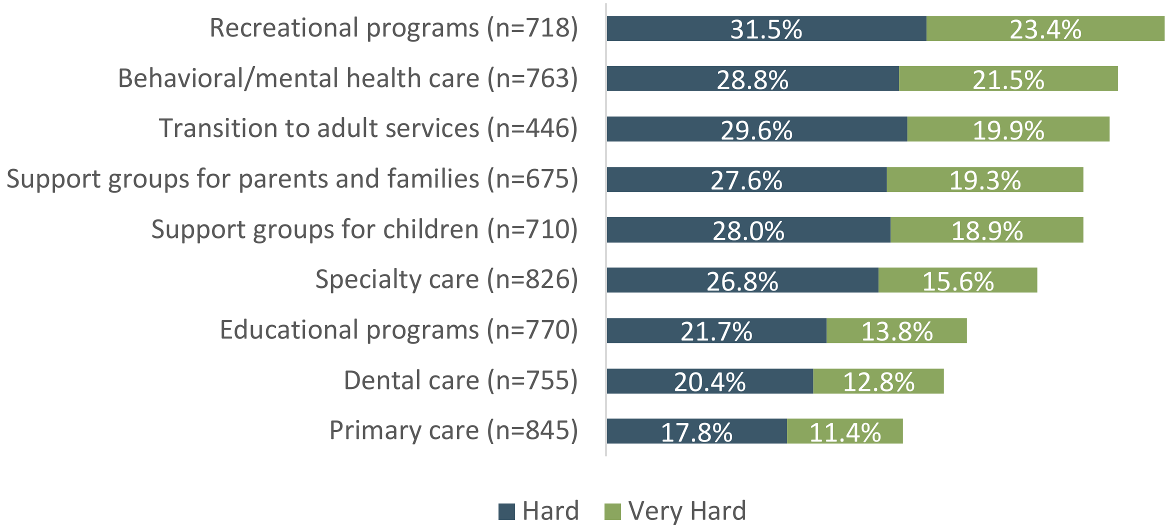
## Appendix E- Community Survey Results

### Table 25. Community Survey Respondent Characteristics

|  | n |  |  |
|---|---|---|---|
| **All Respondents** | 977 |  |  |
| **Parents/Caregivers** | 906 |  |  |
| **Other Respondents** | 71 |  |  |
|  |  |  |  |
| **All Respondent Characteristics** |  |  |  |
| **Race/Ethnicity (n=812)** |  | **Gender Identity (n=810)** |  |
| Black/African American, Non-Hispanic | 89 | Male | 111 |
| Asian, Non-Hispanic | 29 | Female | 678 |
| White, Non-Hispanic | 332 | Transgender | 1 |
| Hispanic/Latino(a) | 251 | Other | 4 |
| Other/Multiracial, Non-Hispanic | 38 | Prefer not to say | 16 |
| **Age (n=808)** |  | **Primary Language Spoken at Home (n=811)** |  |
| 18 years or under | 12 | English | 618 |
| 18-21 years | 3 | Spanish | 152 |
| 22-24 years | 16 | Other | 21 |
| 25-34 years | 163 | Prefer not to say | 8 |
| 35-44 years | 296 | Hindi | 4 |
| 45-54 years | 188 | Portuguese | 4 |
| 55-64 years | 68 | Arabic | 3 |
| 65-74 years | 28 | Chinese | 1 |
| 75+ years | 5 |  |  |
| Prefer not to say | 18 |  |  |
| **Education (n=764)** |  | **Employment Status (n=762)** |  |
| Less than high school | 20 | Employed full-time | 349 |
| Some high school | 35 | Employed part-time | 135 |
| High school graduate | 130 | Student | 18 |
| Some college | 147 | Homemaker | 124 |
| Associate or technical degree/certification | 80 | Disabled | 32 |
| College graduate | 165 | Retired | 22 |
| Postgraduate or professional degree | 150 | Unemployed | 85 |
| Prefer not to answer | 37 | Prefer not to answer | 31 |
| **Income (n=804)** |  |  |  |
| Under $25,000 | 166 |  |  |
| $25,000 to $50,000 | 142 |  |  |
| $50,001 to $75,000 | 115 |  |  |
| $75,001 to $100,000 | 69 |  |  |
| $100,001 to $125,000 | 41 |  |  |
| $125,001 to $150,000 | 35 |  |  |
| $150,001 to $200,000 | 34 |  |  |
| Over $200,000 | 41 |  |  |
| Prefer not to answer | 161 |  |  |
|  |  |  |  |

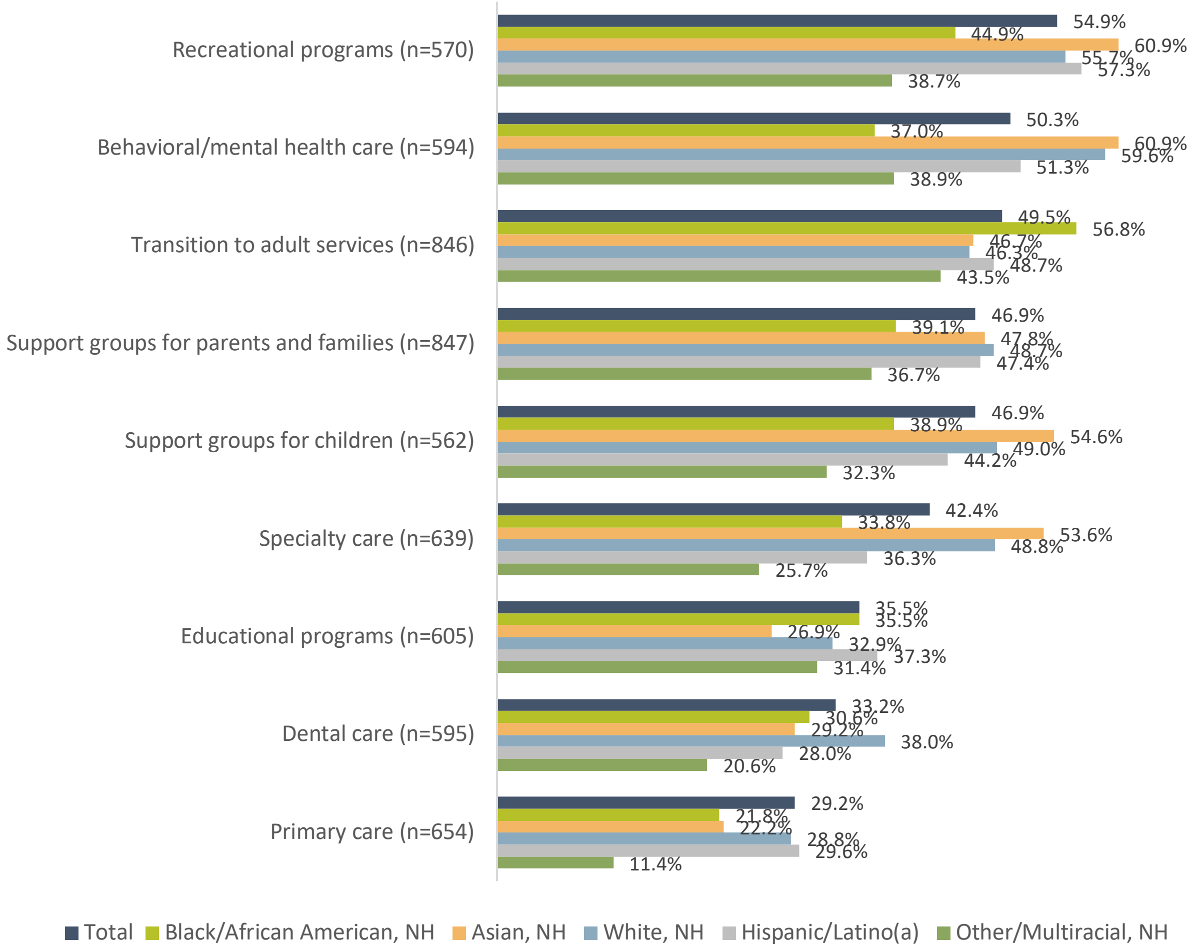
| **Parent/Caregiver Characteristics** | | | |
|---|---|---|---|
| **Race/Ethnicity (n=751)** | | **Age of Children (n=748)** | |
| Black/African American, Non-Hispanic | 81 | Under 5 years | 134 |
| Asian, Non-Hispanic | 28 | 5-9 years | 196 |
| White, Non-Hispanic | 293 | 10-14 years | 170 |
| Hispanic/Latino(a) | 245 | 15-18 years | 62 |
| Other/Multiracial, Non-Hispanic | 37 | Over 18 years | 64 |
| **Child's Insurance Status (n=749)** | | | |
| Public Insurance | 410 | | |
| Private Insurance | 265 | | |

**Figure 45. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, 2022**



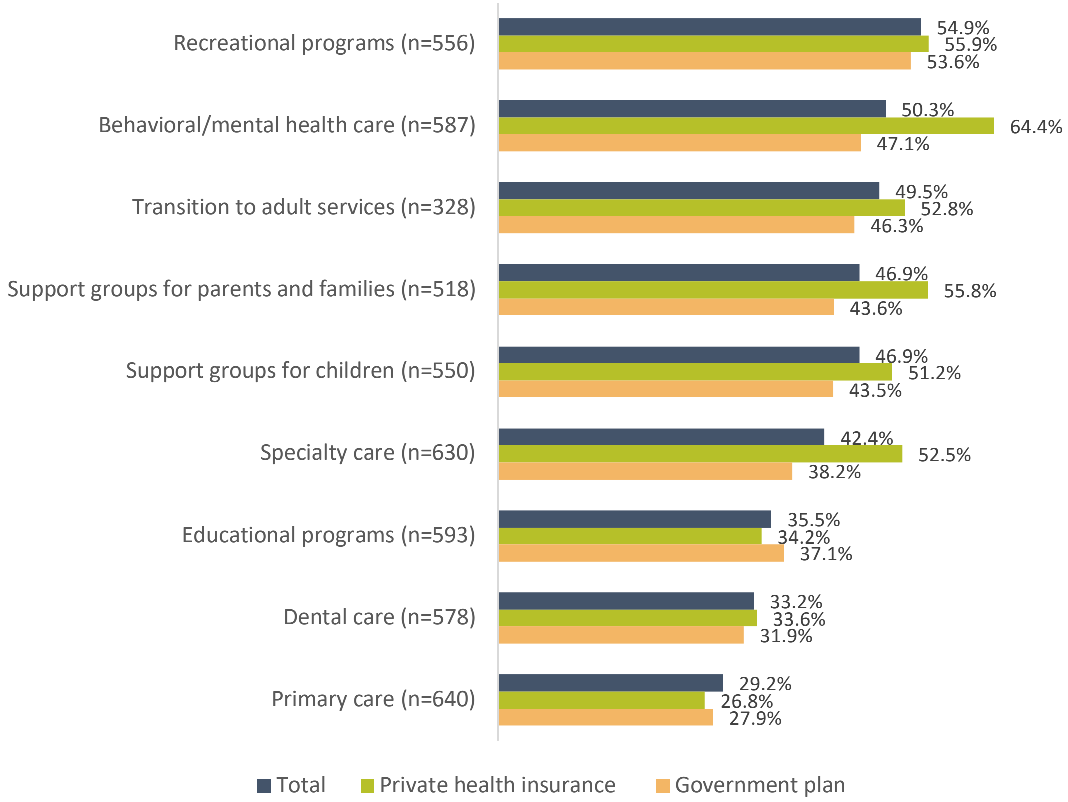
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 46. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, by Race/Ethnicity, 2022**



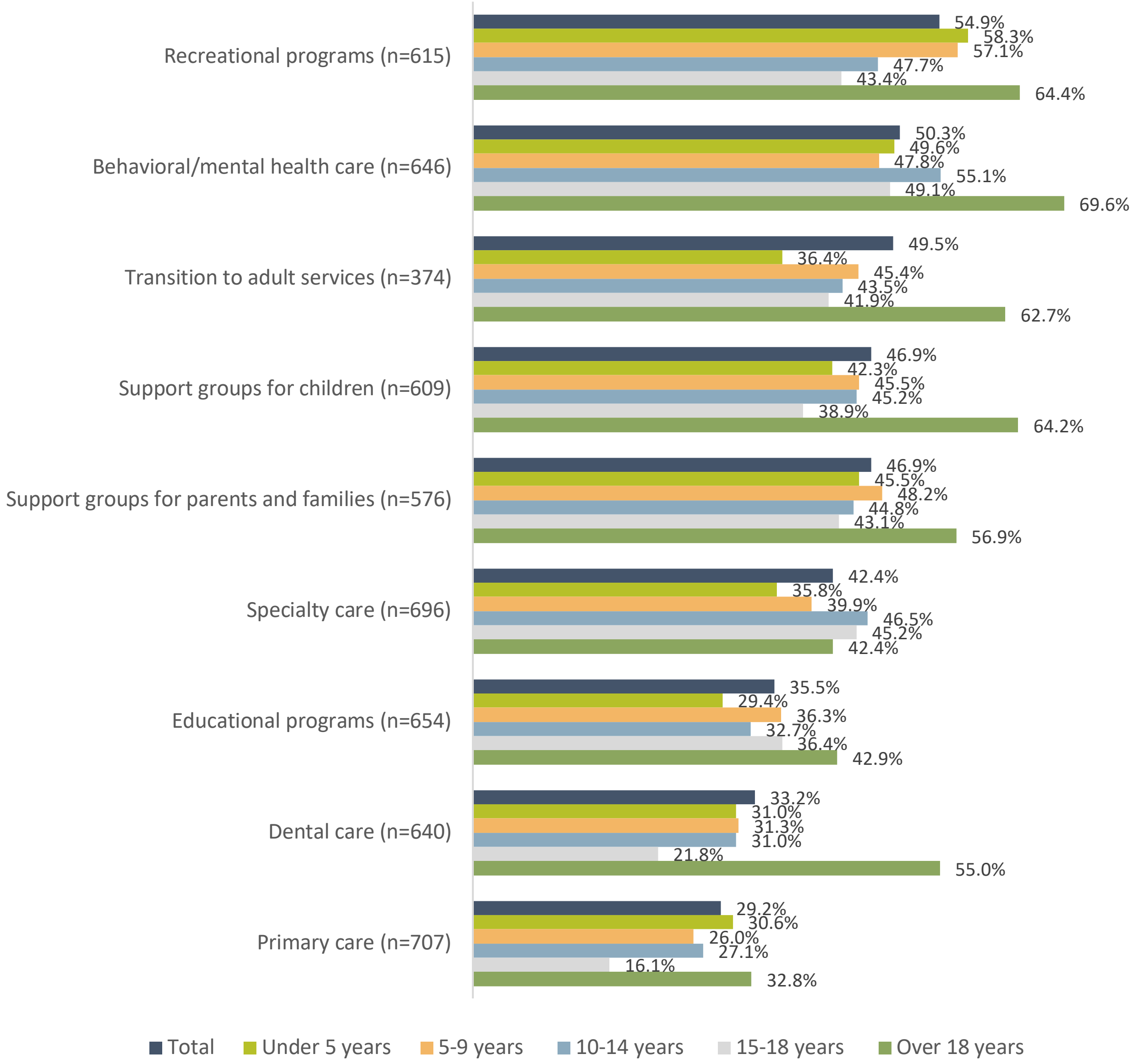
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 47. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, by Insurance Status, 2022**



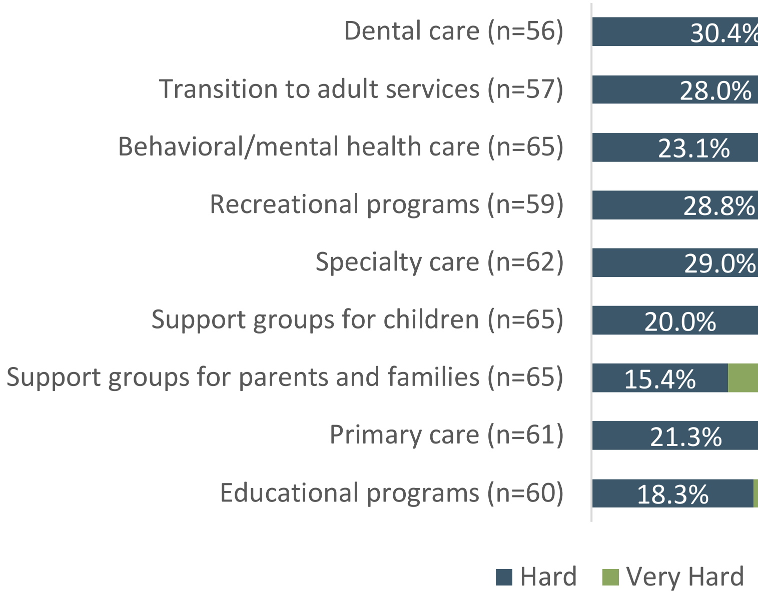
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 48. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for their Children with Special Health Care Needs, among Parents/Caregivers, by Age of Child, 2022**



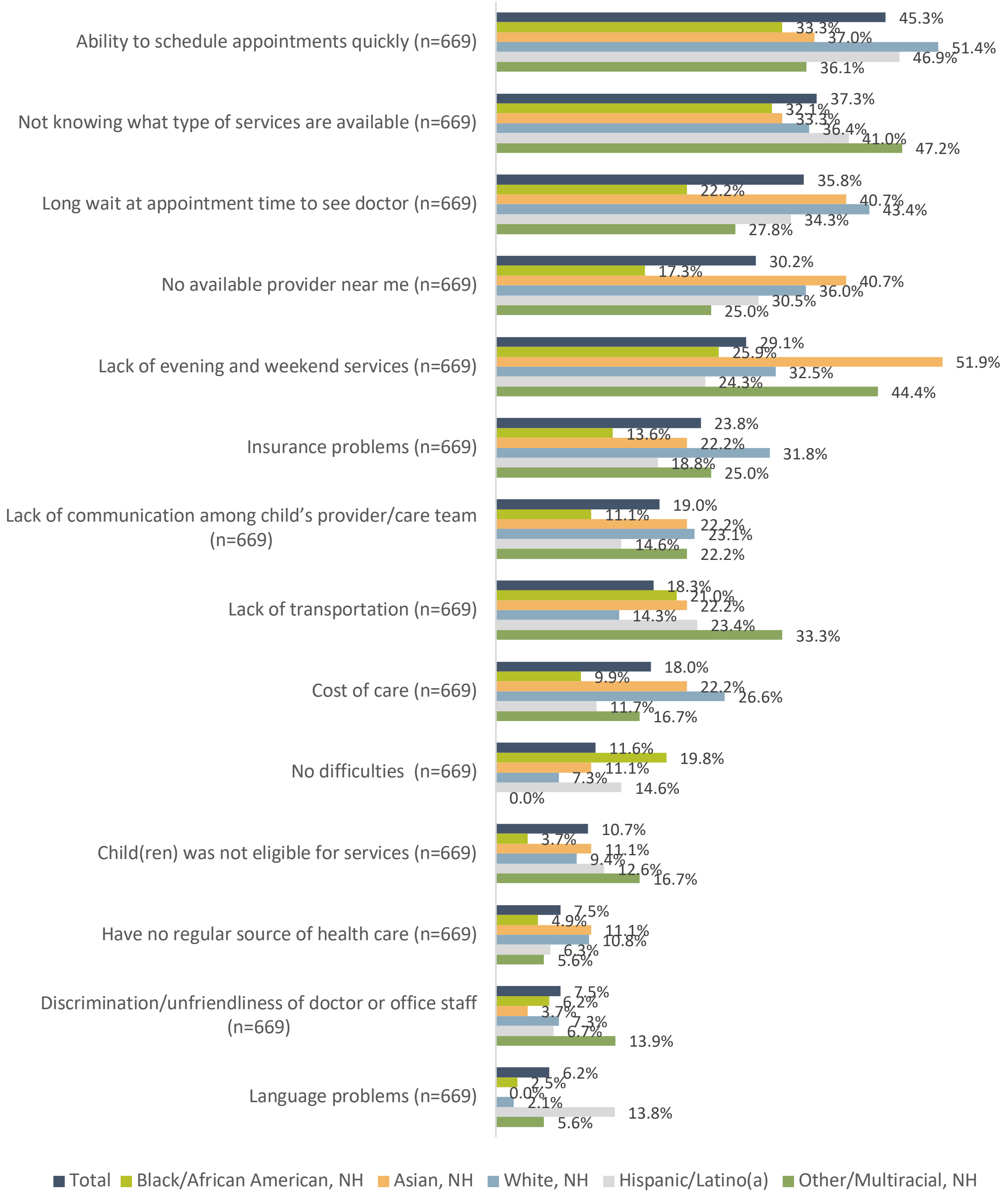
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 49. Percent of Community Survey Respondents Reporting Programs and Services that are Very Hard or Hard to Access for Children with Special Health Care Needs, among Other Respondents, 2022**



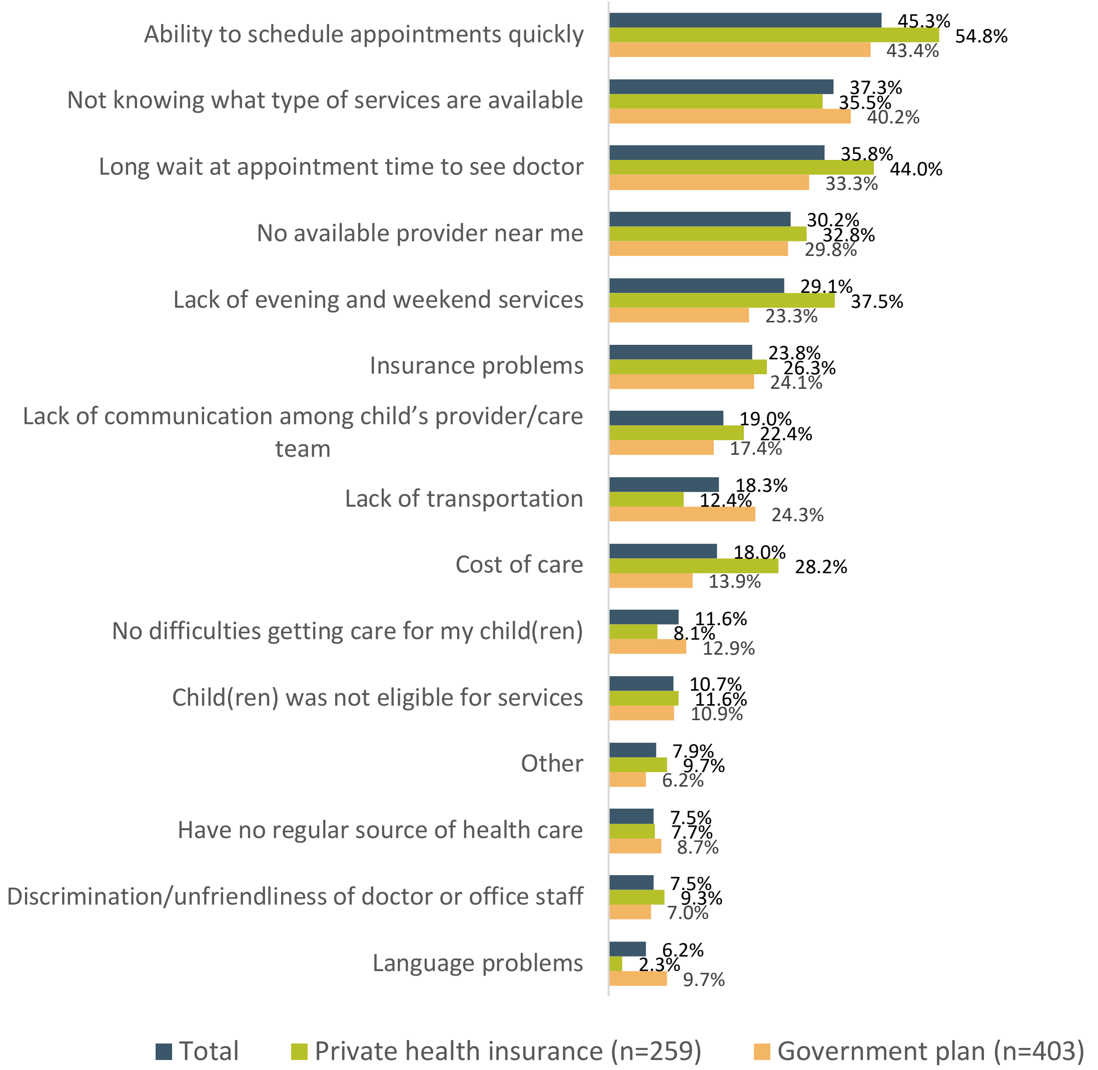
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 50. Percent of Community Survey Respondents Reporting Issues That Make it Difficult to Access Health Care for Their Children with Special Health Care Needs, among Parents/Caregivers, by Race/Ethnicity (N=669), 2022**



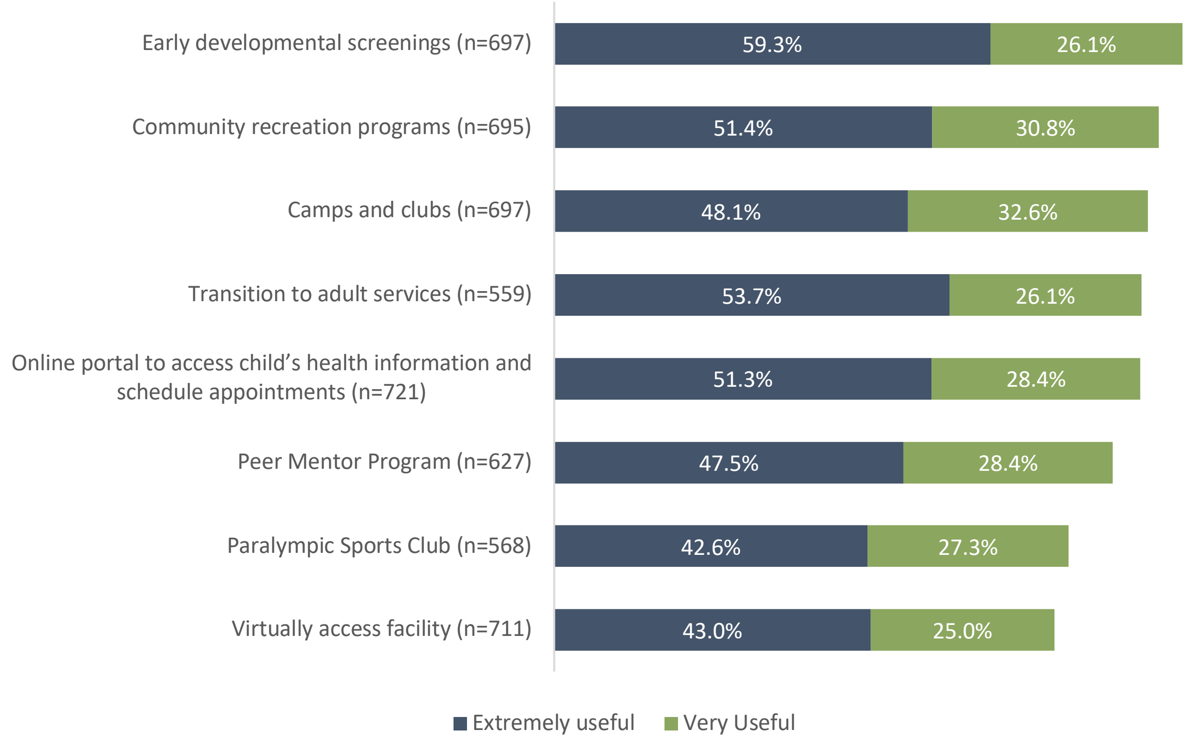
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 51. Percent of Community Survey Respondents Reporting Issues That Make it Difficult to Access Health Care for Their Children with Special Health Care Needs, among Parents/Caregivers, by Insurance Status (N=662), 2022**



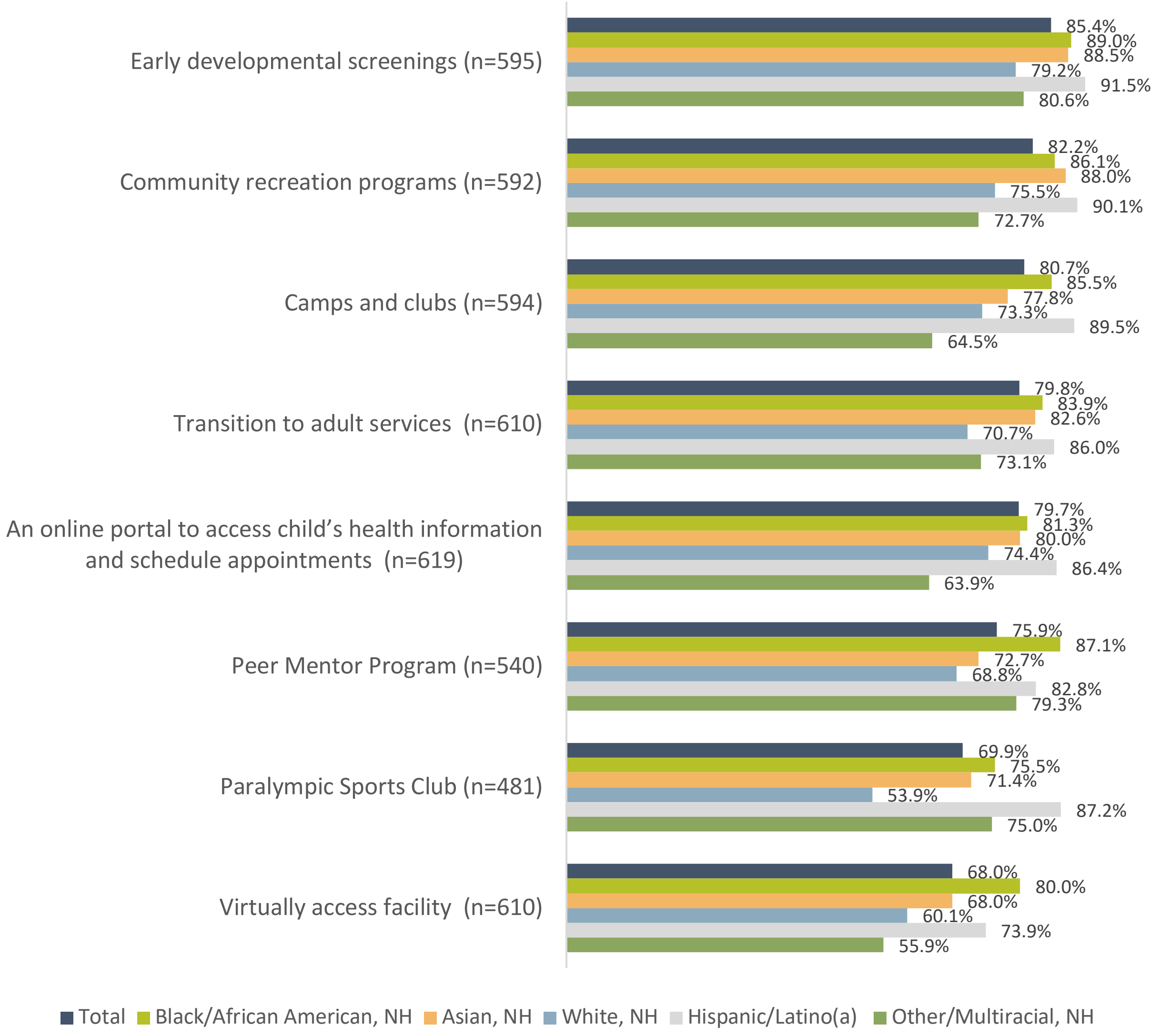
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 52. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, 2022**



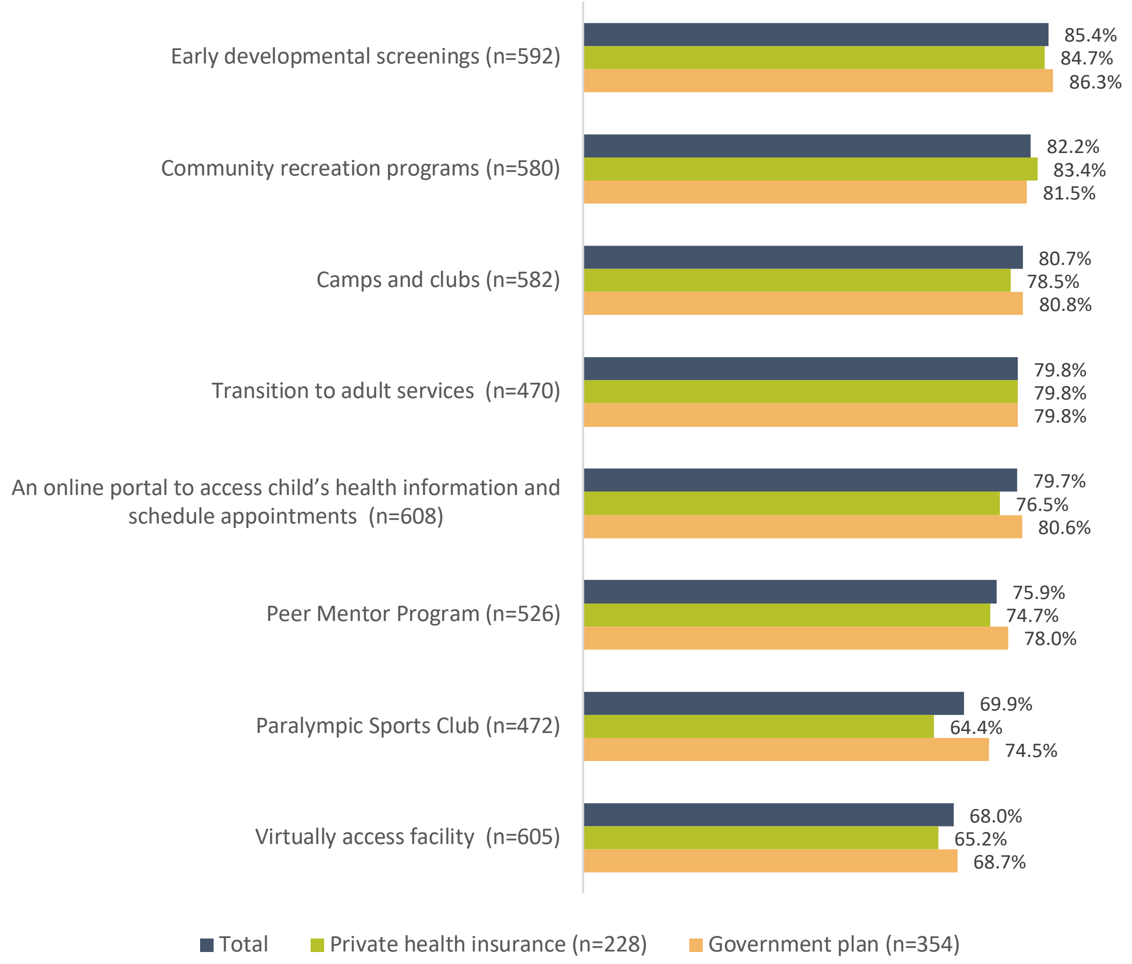
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 53. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, by Race/Ethnicity 2022**



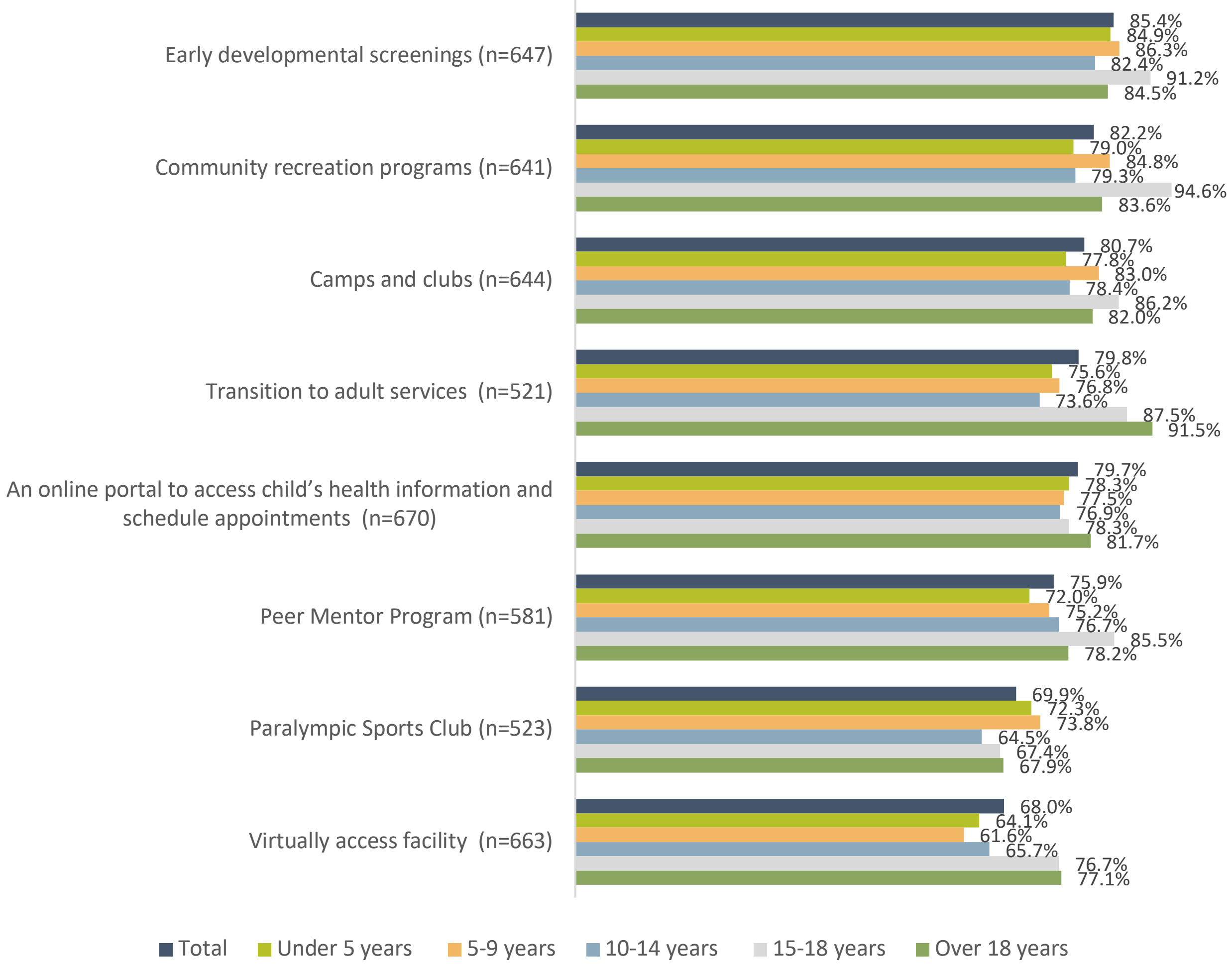
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 54. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, by Insurance Status, 2022**



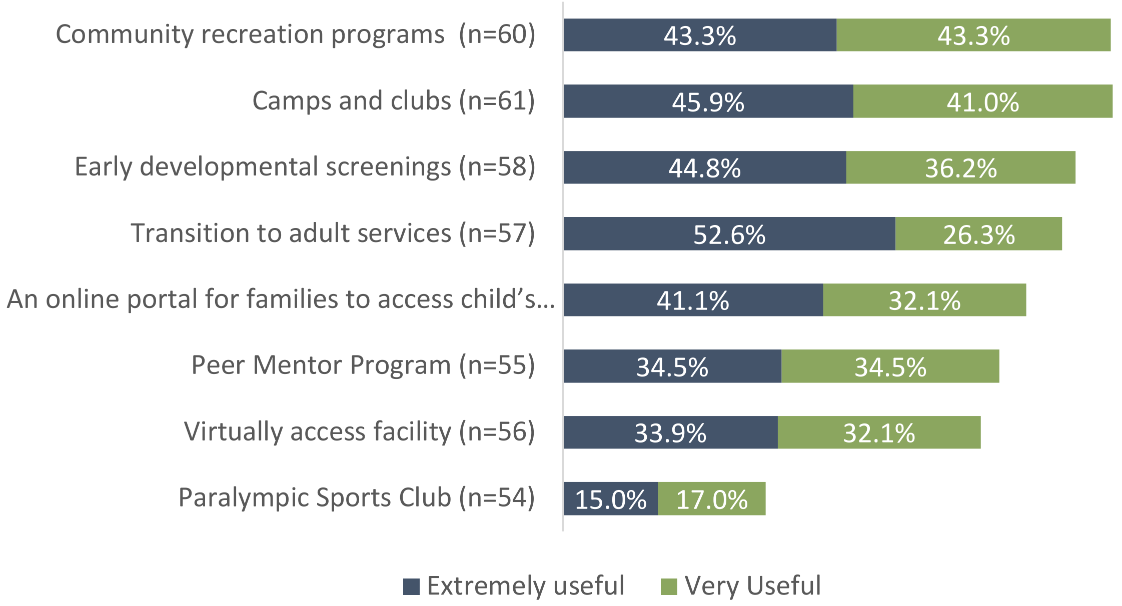
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 55. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Parents/Caregivers, by Age of Child, 2022**



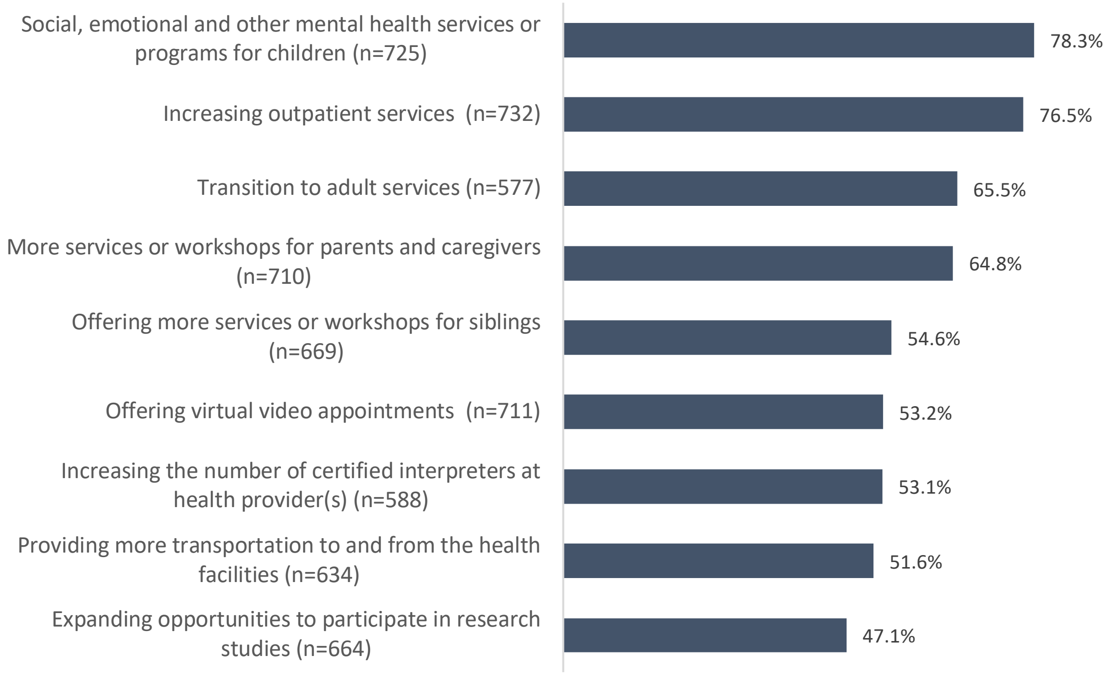
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 56. Percent of Community Survey Respondents Reporting Programs and Services that Would be Extremely Useful or Very Useful for their Children with Special Health Care Needs, among Other Respondents, 2022**



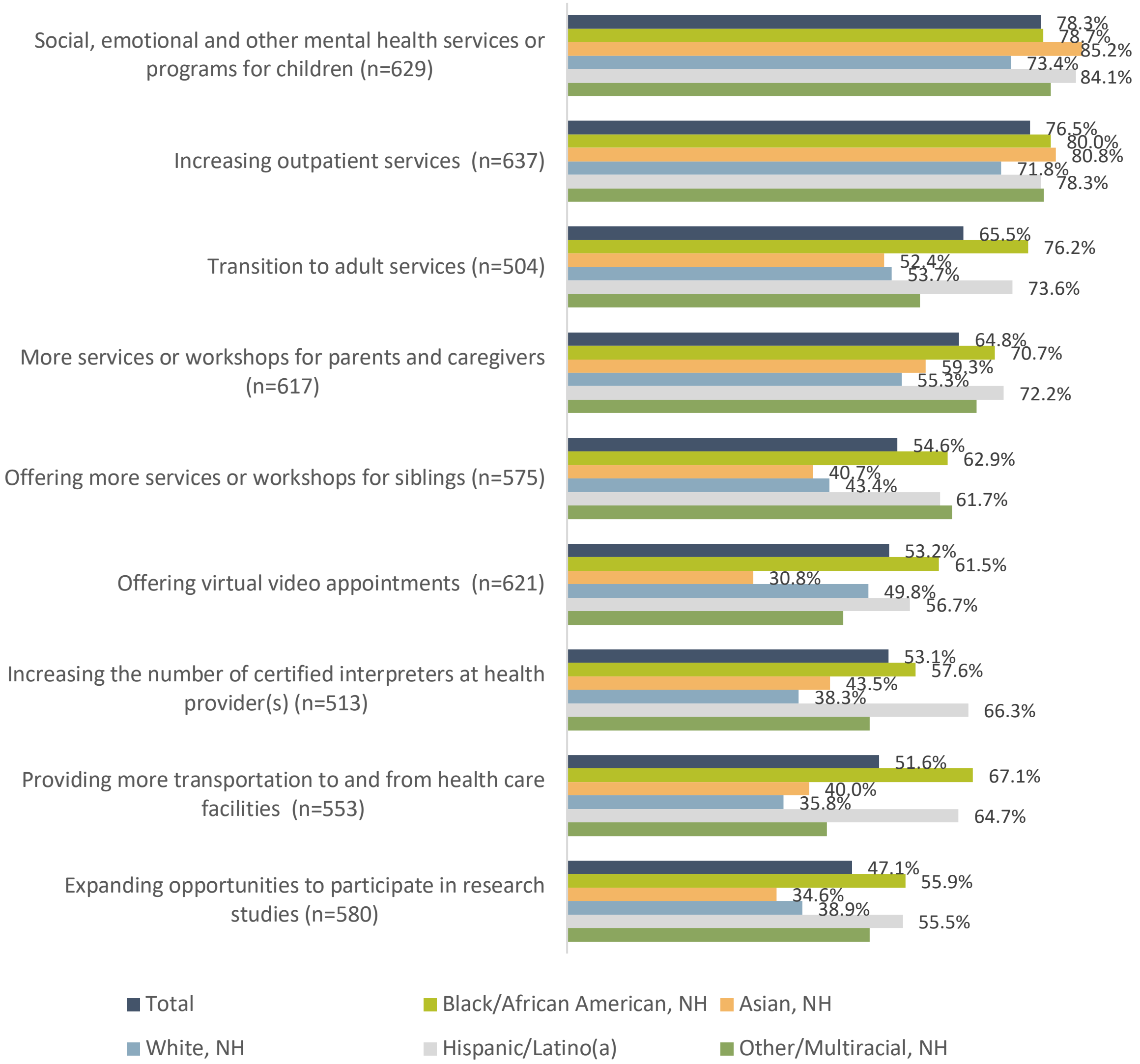
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 57. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, 2022**



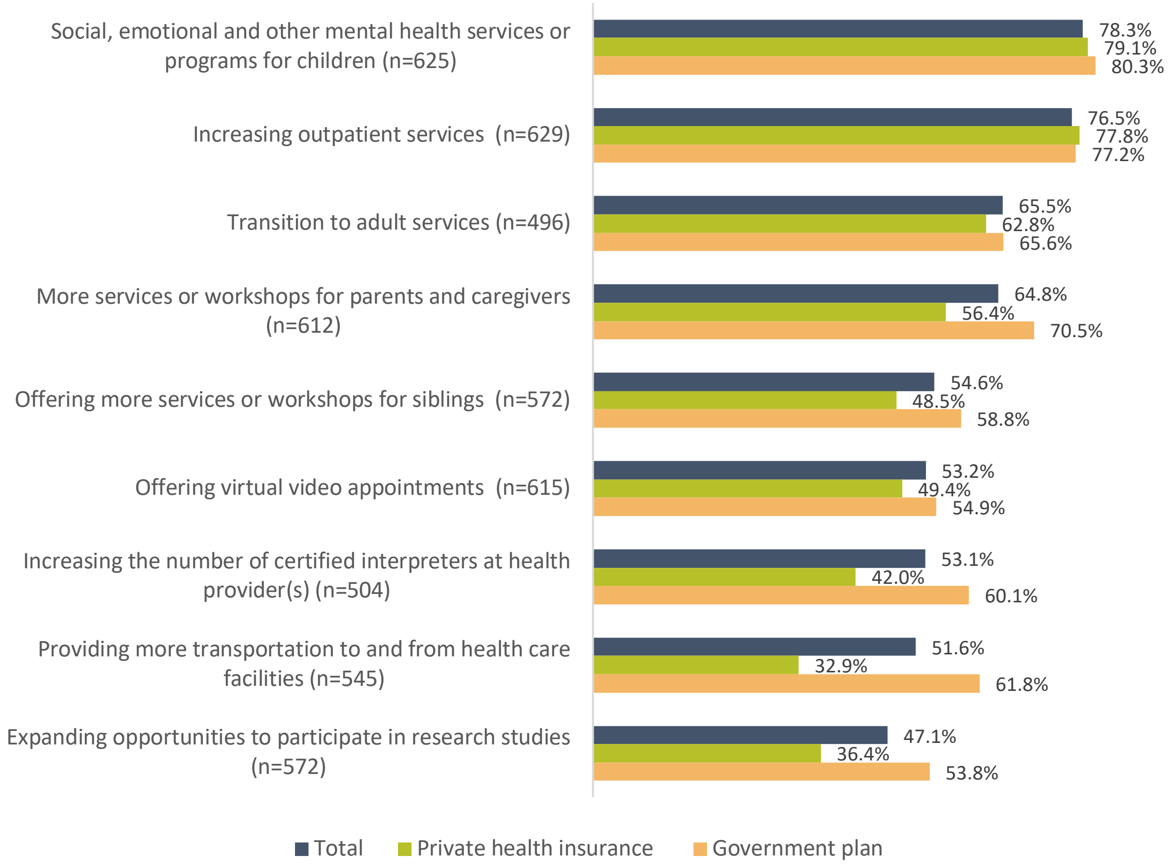
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 58. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Race/Ethnicity, 2022**



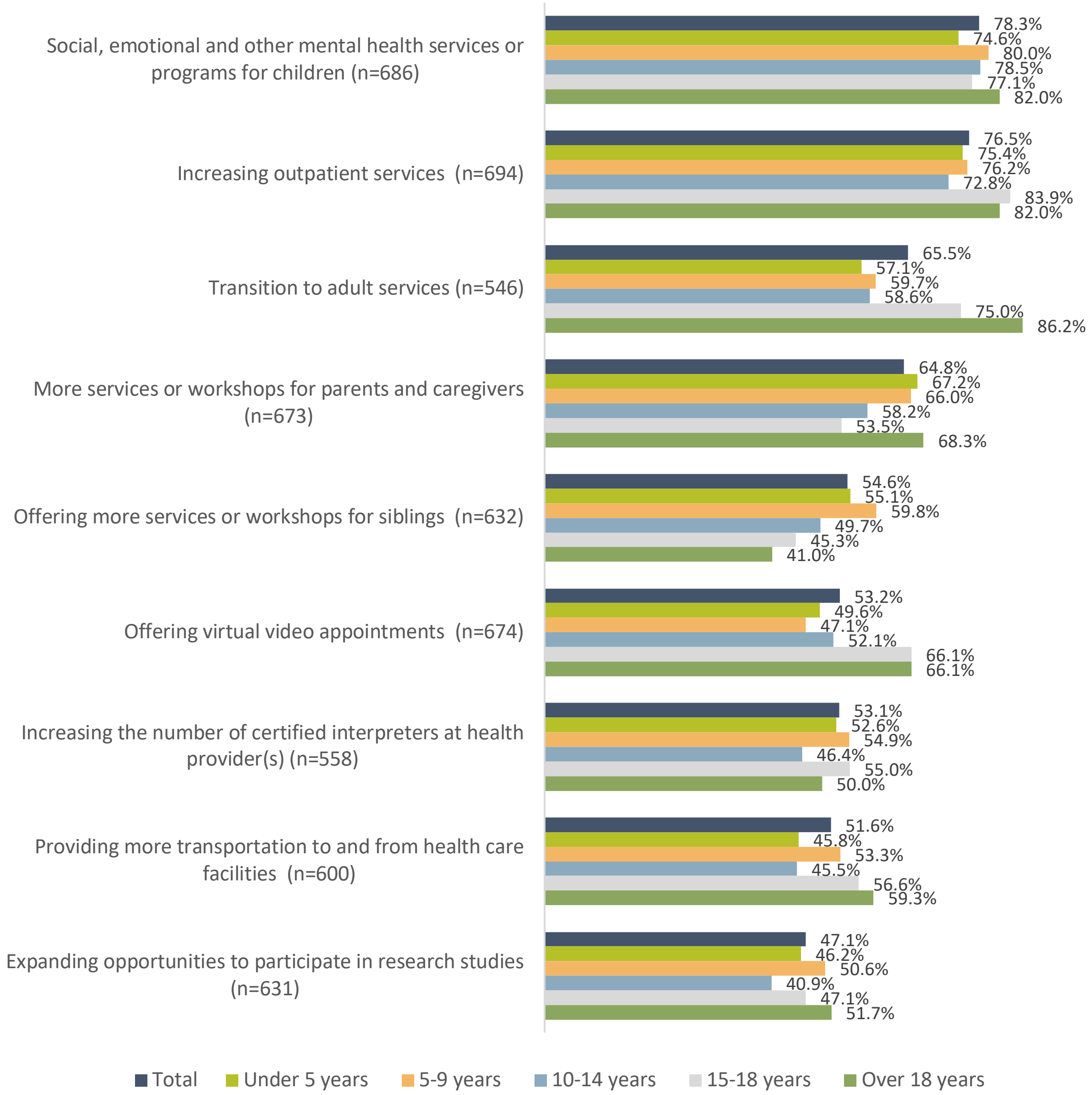
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 59. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Insurance Status, 2022**



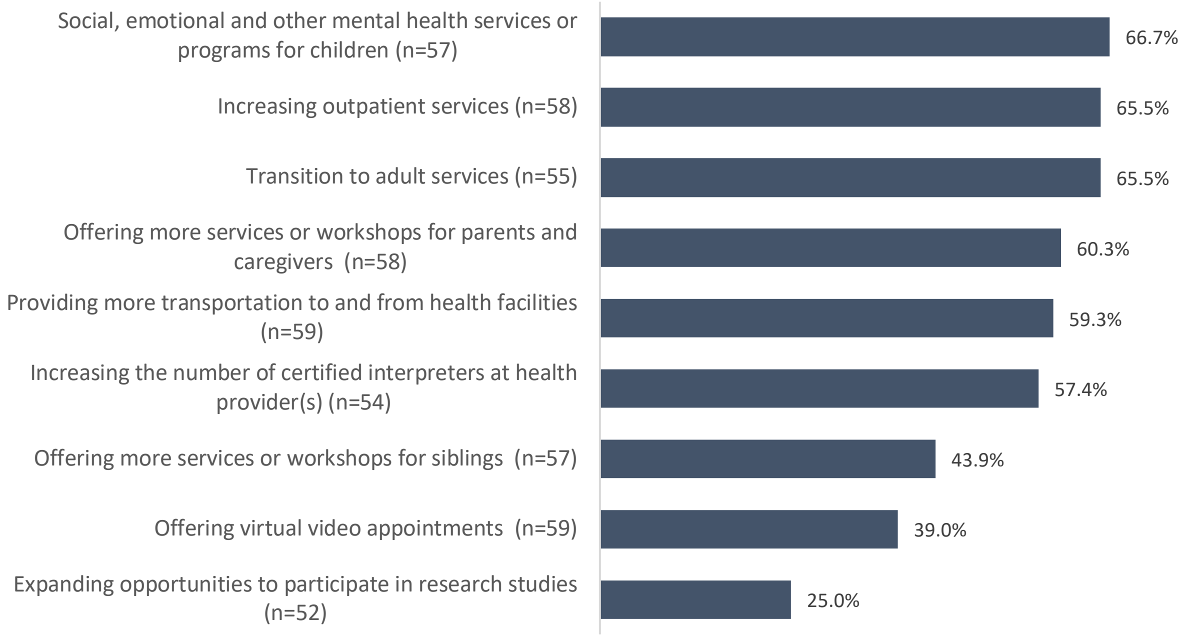
DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 60. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Parents/Caregivers, by Age of Child, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Figure 61. Percent of Community Survey Respondents Reporting Programs and Services that Should be High Priority, among Other Respondents, 2022**



DATA SOURCE: Community Health Needs Assessment Survey Data, Health Resources in Action, 2022

**Appendix E- Resource Inventory**

| Name | Services | Locations | Website |
|---|---|---|---|
| **Academy Learning Center** | Center offers comprehensive programing for Students with Autism or Multiple Disabilities from ages 3-21 | Monroe, TWP | https://www.escnj.us/domain/110 |
| **Alpha School** | School provides educational, therapeutic and support services for students ages 5- 21 with special needs | Jackson, NJ | https://alphaschool.com/contact-us/ |
| **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 | https://www.archwayprograms.org/contact-locations |
| **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 | https://www.asah.org/contact-us/ |
| **Association for Special Children and Families (ASCF)** | ASCF is a community-based organization for families of children with disabilities | Hewitt, NJ | https://ascfamily.org/category/contact-us/ |
| **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 | https://www.autismnj.org/connect/contact-us/ |
| **Autism Speaks** | Autism Speaks Enhances lives today and is accelerating a spectrum of solutions for tomorrow | Princeton, NJ | https://www.autismspeaks.org/contact-us |

| Name | Services | Locations | Website |
|---|---|---|---|
| **Autism Spectrum Education Network (ASPEN)** | ASPEN provides families and individuals who lives are affected by Autism Spectrum Disorders and Nonverbal learning disabilities | Edison, NJ | https://aspennj.org/contact-aspen |
| **Bethel Ridge** | Sharing service by conducting classes for people with special needs to provide greater opportunities for kids | Basking Ridge, NJ | https://bethelridgenj.org/J3/ |
| **Cambridge School** | specialize in educating students with dyslexia, ADHD, and other language-based learning disabilities | Pennington, NJ | https://www.thecambridgeschool.org/contact-us/ |
| **Children's Center at Monmouth County** | Serving the special need for children and their families | Neptune, NJ | http://www.ccprograms.com/ContactUs.aspx |
| **Community Access Unlimited (CAU)** | Provide services for youth with intellectual and developmental disabilities | Elizabeth, NJ | http://www.caunj.org/?page_id=190 |
| **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 | https://www.cpcbehavioral.org/neptune |
| **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<br>Deron II Montclair, NJ | https://www.deronschool.org |
| **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 | http://www.devereux.org/site/PageServer?pagename=centers |

| Name | Services | Locations | Website |
|---|---|---|---|
| **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 | https://boggscenter.rwjms.rutgers.edu/ |
| **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 | https://www.easterseals.com/nj/who-we-are/contact-us/ |
| **First Children Services** | Life changing outcomes for Exceptional Kids. Educate students with multiple disabilities | Fanwood, NJ | https://www.firstchildrenservices.com/about-us/contact-us/ |
| **Greater Metro West ABLE'S** | Local Jewish organizations | Essex, Morris, Somerset, Sussex and Union | https://www.greatermetrowestable.org/?utm_source=Kveller&utm_medium=ABLE-resource-page&utm_campaign=GMWABLE |
| **Harbor School** | Providing an alternative program to the public-school districts for students with disabilities. | Eatontown, NJ | https://harborschool.com/contact-us/ |
| **Hawks wood School** | Provides high quality special education services to children with complex, multiple disabilities, including autism | Eatontown, NJ | http://hawkswoodschool.net/contact-us/ |
| **Hudson Milestone** | Provides in-home respite and early intervention services for families and children with developmental disabilities | Jersey City, NJ | http://www.hudsonmilestones.org/contact-us/ |

| Name | Services | Locations | Website |
|---|---|---|---|
| **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 | https://www.ladacin.org |
| **Need Quest** | Local directory of special needs resources for parents, children and families in New Jersey | Westfield, NJ | https://needquest.com/contactus |
| **New Jersey Alliance for Children, Youth and Families** | NJACF collaborate to ensure brighter futures for children, youth and families | Hamilton, NJ | http://njacyf.org/about-us |
| **New Jersey Children System of Care (CSOC)** | Provides volunteer services for children through Perform Care, Contracted Service Administrator for CSOC | Hamilton, NJ | https://www.mercerresourcenet.org/about/about-new-jersey-s-children-s-system-of-care-csoc/ |
| **New Jersey Institute for Disabilities** | NJID offers specialized facilities, programs and supports throughout the state of New Jersey for children and youth | Edison, NJ | https://www.njid.org/children-programs |
| **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 | http://newroadschool.com/contact-nrs/ |
| **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 | https://www.performcarenj.org/index.aspx |
| **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 | http://www.noahsarkinstitute.org/contact.html |
| **Oakwood School** | Private school for disabled children forms ages 11-21 years | Tinton Falls, NJ | http://oakwoodschool.net/contact/ |

| Name | Services | Locations | Website |
|---|---|---|---|
| **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 | https://www.poac.net |
| **Princeton Child Development Institute (PCDI)** | Providing Lifelong Services to People with Autism | Princeton, NJ | http://pcdi.org/early-intervention/ |
| **Puzzle Place center For Autism** | A Playful Approach to Serious Therapy | Freehold, NJ | https://thepuzzleplace.org/our-approach/ |
| **Rugby School** | Provide a nurturing environment for special students to maximize their potentials while exploring their unique abilities | Wall Township, NJ | http://www.rugbyschool.org/our-school/about-rugby-school/ |
| **School of Children with Hidden Intelligence (SCHI)** | SCHI provides educational and therapeutic services by certified professional staff to children with disabilities. | Lakewood, NJ | https://www.schischool.org/contacts/ |
| **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 | https://www.theshorecenter.org/Page/1 |
| **SPAN (Statewide Parent Advocacy Network)** | Guide to developing and conducting an effective group | Newark, NJ | https://www.spanadvocacy.org |
| **Special Dragons** | Providing exercise and self- defense programs for Special Needs Students | Northern New Jersey | http://www.specialdragons.us/index.html |
| **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 | http://www.specialkidsfund.org |

| Name | Services | Locations | Website |
|---|---|---|---|
| **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 | https://www.arcnj.org/index.html |
| ***The Arc of Essex County*** | Provides services for people with intellectual and developmental disabilities and their families | Livingston, NJ | https://arcessex.org |
| ***The Arc of Bergen & Passaic Counties*** | Provides services for people with intellectual and developmental disabilities and their families | Hackensack, NJ | https://arcbp.org |
| ***The Arc of Hudson County*** | Provides services for people with intellectual and developmental disabilities and their families | Hampton, NJ | https://archunterdon.org |
| ***The Arc/Mercer, Inc*** | Provides services for people with intellectual and developmental disabilities and their families | Ewing, NJ | https://arcmercer.org |
| ***The Arc of Middlesex*** | Provides services for people with intellectual and developmental disabilities and their families | North Brunswick, NJ | https://arc-middlesex.org |
| ***The Arc of Monmouth*** | Provides services for people with intellectual and developmental disabilities and their families | Tinton Falls, NJ | https://arcofmonmouth.org |
| ***The Arc, Ocean County Chapter*** | Provides services for people with intellectual and developmental disabilities and their families | Lakewood, NJ | https://arcocean.org |
| ***The Arc of Somerset*** | Provides services for people with intellectual and developmental disabilities and their families | Manville, NJ | https://thearcofsomerset.org |

| Name | Services | Locations | Website |
|---|---|---|---|
| ***The Arc of Union*** | Provides services for people with intellectual and developmental disabilities and their families | Springfield, NJ | https://arcunion.org |
| ***The Arc of Morris County*** | Provides services for people with intellectual and developmental disabilities and their families | Morris Plains, NJ | https://arcmorris.org |
| **The Midland School** | Helping students with disabilities reach their highest potential | North Branch | https://midlandschool.org |
| **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 | http://ucpofhudsoncounty.org/about-us/ |
| **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 | http://www.ycs.org/index.php/contact-us/ |

## Appendix F- Outcomes and Results Report of the Previous Implementation Plan

Children's Specialized Hospital®
An RWJBarnabas Health facility

# Community Health Needs Assessment

## *Implementation Plan 2021*

# Introduction

In 2019, 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 survey and meetings with local health officials. The plan can be accessed here.

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 three selected priority areas*:

- Behavioral/Mental Health Services
- Transitional Services
- Enhanced Access

**The three focus areas do not represent the full extent of CSH’s community benefit activities or its support of the community’s health needs. Other needs identified through the CHNA may be better addressed by other agencies/organizations or deferred to another timeframe. Other significant needs identified include insurance issues, limited access to dental services for North Jersey residents, and not having a full understanding of what services are available.*

# Behavioral/Mental Health Services

## Goals & Strategies

| Goal | Strategy | Outcome |
|---|---|---|
| Address the mental health complexities of the current CSH patient population by exploring build, buy and partnership options (e.g., IP and OP Med Psych services, learning centers, etc.) | Work with RWJBH System to establish access for employee's children to mental health services at CSH and System transitional programs if needed. | This goal was put on hold while the RWJBH System established the pediatric service line. |
| Invest in technology to improve access, operational efficiencies, cost effectiveness, physician and support services | Implement TeleMed services for Primary Care sick visit triage, Psychiatry, Psychology, and IP discharge follow-ups using RWJBH standard tools by 10/1/2020. | Telemed services were rolled out for all CSH disciplines in Spring 2020. |

# Transitional Services

## Goals & Strategies

| Goal | Strategy | Outcome |
|---|---|---|
| Create and implement an Employee Readiness and Placement Program for teens and young adults with special healthcare needs | 1. Increase the total number of students enrolled in the Work Readiness Academy at our Mountainside facility to at least 6 students by 10/31/2020 for the '20-'21 academic school year.<br>2. Develop a repository of tools and/or resources that will facilitate and/or improve integrated work environments for teens and young adults with special healthcare needs by 12/31/2020. | 1. The Work Readiness Academy was put on hold for the '20-'21 school year due to the pandemic. However, CSH did host six students for the '21-'22 school year and plan to host at least another 6 students for the upcoming '22-23 school year.<br>2. 30% of the repository tools and resources have been developed through a JV with Spectrum Hub. There is currently a leadership change occurring within the JV which has caused a pause, but the development of this repository should continue by the end of '22. |
| Facilitate volunteer activities promoting community service in key geographies | CSH volunteers will place 2-3 young adult volunteers with special healthcare needs per school semester to promote employment readiness | This goal was achieved with CSH placing 5-7 young adults volunteers with special healthcare needs per school semester. |
| Coordinate with RWJBH leadership in expanding programs to target the young adult population | Partner with The Boggs Center, CDID and Community Programs to facilitate four parent panels on 'Transitions' | Through a partnership with The Boggs Center, four free educational seminars regarding 'Transitions' were presented to parents and caregivers of children with special healthcare needs in 2020. |

# Enhanced Access

| Goal | Strategy | Outcome |
|---|---|---|
| Invest in technology to improve access, operational efficiencies, cost effectiveness, physician and support services | Implement Telemed services for Primary Care sick visit triage, psychiatry, psychology, and IP discharge follow-ups using RWJBH standard tools by 10/1/2020. | Telemed services were rolled out for all CSH disciplines in Spring 2020. |
| Invest in predictive analytics and patient monitoring to help manage CSH's patient population and minimize costs by addressing potential barriers to care in a more proactive manner | Identify and begin to implement at least one new technological solution that broadens access to healthcare for children with special healthcare needs and their families by 10/1/2020. | CSH encountered some delays due to the pandemic but finalized an agreement in November 2021 and started a JV with an analytics company, Pinnacle Solutions. The JV is called Predictive Health Solutions (PHS). PHS is a new company which will look at analytical ways to address healthcare problems. The first solution being worked on is the no-show solution which addresses the problem of patients who miss their appointments (either by not showing up or cancelling at the last minute). Currently working with IT and operations to implement the solution and are targeting a Fall 2022 launch date. |
| Improve pediatric therapy access points through the opening of new outpatient centers to reduce new patient visit and follow-up appointment wait times and expand into new markets. | 1. Expansion of therapy services to Jersey City by end of Q4 2020.<br>2. Begin planning and start construction of new Union site including transition plan for Mountainside in Q3 2020.<br>3. Design and initiate construction of new Monmouth site by end of Q3 2020. | 1. This goal will be achieved in Fall 2022.<br>2. This goal was achieved in accordance with the timeline stated.<br>3. Design of the new Monmouth site started in Q1 2020 and construction started in Q2 2021. |