

May 26, 2016

Children's Specialized Hospital 2016 Community Health Needs Assessment

Final Report

Submitted to:



Health Resources in Action
Advancing Public Health and Medical Research

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EXECUTIVE SUMMARY

Background

Children’s Specialized Hospital (CSH) is a 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 to developmental and behavioral issues. In December 2015, CSH contracted with Health Resources in Action (HRiA), a non-profit public health organization in Boston, to conduct a community health needs assessment. This report describes the process and findings from this effort. The assessment process was undertaken to achieve the following overarching goals:

- To determine perceptions of the health-related needs of children with special health care needs and their families
- To build upon CSH’s 2013 assessment and identify current barriers to accessing health care, as well as gaps and challenges in care, for children with special health care needs and their families
- To explore opportunities for addressing identified needs and filling gaps

Methods

To identify barriers to accessing care, gaps in and challenges with existing health care services for children with special health care needs and their families, and possible solutions to these issues, the assessment process included: a review of existing secondary data, an online survey with parents, and interviews with key stakeholders at CSH and in the community. The parent survey was completed by 294 respondents, and 11 key informant interviews were conducted by phone with stakeholders internal and external to CSH (see Appendix A).

Findings

The following provides a brief overview of key findings that emerged from this assessment. Gaps, barriers, and challenges are presented broadly, reflecting services that are generally available in the community for children with special health care needs and their families. Any gaps, barriers, and challenges specific to CSH are noted. After each gap, barrier, or challenge, suggestions from assessment participants for CSH are presented.

Social and Economic Context of the Region

- **Demographic Diversity:** In New Jersey, 30.3% of the population speaks a language other than English at home. Among the nine counties in which CSH facilities are located, the percentage of the population speaking a language other than English at home ranges from 26.5% (Atlantic County) to 59.3% (Hudson County).
- **Poverty Status:** Overall, 8.1% of families in New Jersey live below the poverty line. Among the nine counties in which CSH facilities are located, the percentage of families living below the poverty line ranges from 3.5% (Somerset County) to 15.0% (Hudson County).

Population of Children with Special Health Care Needs in New Jersey

- **Population of Children with Special Health Care Needs:** The percentage of children with special health care needs in New Jersey (19.0%) is similar to the percentage in the U.S. overall (20.0%). However, in 2013, a higher percentage of students aged 6 to 21 received special education services in New Jersey (11.6%) compared to the U.S. overall (8.4%).

Perceptions of Existing Services for Children with Special Health Care Needs and their Families

- **General Perceptions of Services:** A majority of key informant interviewees described a fragmented health care system that can be challenging for children with special health care

needs and their families to navigate. Interviewees also acknowledged that services and resources can vary greatly depending on a family’s insurance coverage, socioeconomic status, language, and immigration status.

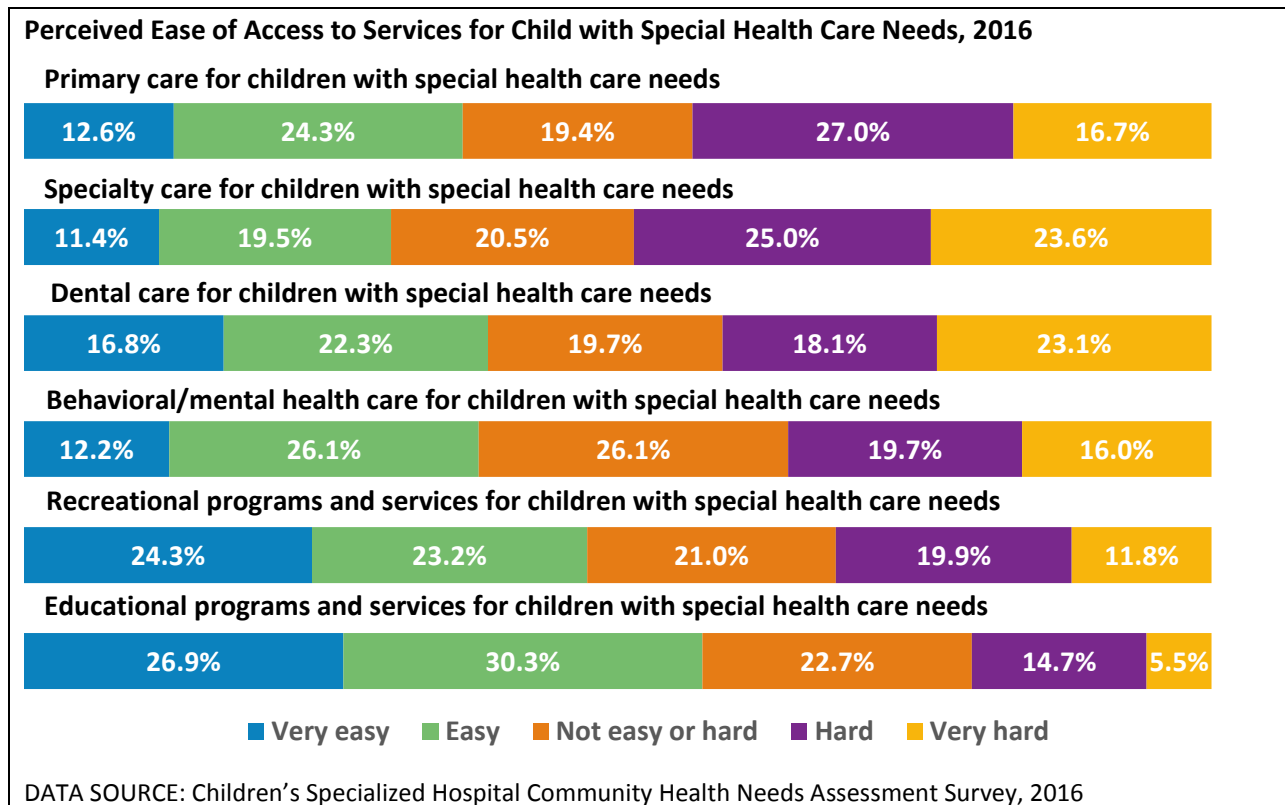
➤ **Perceptions of Children’s Specialized Hospital:**

CSH was described as an institution that provides “extraordinary,” high quality services and truly cares about the patients it serves and their families. CSH was also frequently described as an innovator, a leader, and, in the words of one interviewee, a “really progressive institution.”

“We recommended this hospital... because of the friendliness and great professionalism.... the overall feel [our] boys had was not of being scared but at ease.” – Survey respondent

Gaps in Existing Services and Service Suggestions for Children with Special Health Care Needs and Their Families

In the assessment survey, respondents rated the ease of accessing a variety of specific services. As shown in the figure below, nearly half of respondents (48.6%) reported that specialty care was “hard” or “very hard” to access and 43.7% of respondents found it “hard” or “very hard” to access primary care:



Medical and Behavioral Health Services

- **Gaps:** Interview and survey respondents frequently noted that, due to a limited supply of certain types of providers in the community, there can be long wait times for appointments. In particular, survey and interview respondents frequently stated that more pediatric mental health providers, including therapists, psychologists, psychiatrists, and developmental pediatricians, as well as neurologists are needed. A lack of specialty care, including gastroenterology and endocrinology, was also described by some interview and survey respondents. A few survey respondents noted a need for dentists for children with special

health care needs. While primary care for children with special health care needs was rated “hard” or “very hard” to access by 43.7% of survey respondents (see figure above), it was not mentioned frequently among the open-ended survey responses or during the interviews.

- **Suggestions for CSH:** Many survey and interview respondents stated that CSH should have more behavioral health personnel, particularly to lessen wait times for appointments, and Applied Behavior Analysis therapy was frequently requested. In addition to mental health providers, a few interviewees and some survey respondents noted that there is a need for more pediatric sub-specialists that provide particular types of care such as pediatric gastroenterology and oncology. Lastly, some survey respondents suggested that CSH consider providing dental care.

Social and Recreational Programs and Services

- **Gaps:** Recreational programs and services for children with special health care needs were rated “easy” or “very easy” to access by almost 50% of survey respondents. While overall these services were perceived as being relatively accessible, a few interviewees described the perception that many resources and services exist for children with autism, but one interviewee noted that in comparison, activities such as social programs for children with other diagnoses seem quite limited. Also, many survey respondents stated that they were unaware of CSH’s recreational offerings.
- **Suggestions for CSH:** Survey respondents frequently requested group sessions that allow children with special health care needs to interact socially, develop social skills, and benefit from peer support. Many survey respondents stated that more sports and physical activity programs should be offered. Camps, arts and crafts, music programs, and organized outings were also mentioned.

“Social interaction groups among [peers are needed] ... This may help [kids] know that they aren't alone.” – Survey respondent

Support for Parents, Caregivers, and Siblings

- **Gaps:** Survey and interview respondents described a need for support and education for parents, caregivers, and siblings of children with special health care needs. Interviewees and a few survey respondents also noted a need for more respite care.
- **Suggestions for CSH:** Survey respondents frequently suggested that CSH offer support groups to help parents, caregivers, and siblings understand and cope with diagnoses. Survey respondents also suggested educational workshops, for example, teaching parents how to address behavior issues at home and teaching siblings how to play together. Many survey respondents also requested guidance on navigating Individualized Education Plans.

Transitioning to Community and Adult Care

- **Gaps:** A few interviewees and survey respondents noted that the transition to adult health care is difficult, while others mentioned challenges finding community activities and support.
- **Suggestions for CSH:** Assessment participants suggested that CSH could support families during transitions by facilitating connections with community programs and adult providers.

Barriers and Challenges in Accessing and Utilizing Services and Suggestions for Improvement

Location of Services, Transportation to Services, and Scheduling Barriers

- **Barriers and Challenges:** Interviewees described transportation barriers, and also noted that evening and weekend appointments are not consistently available. Similarly, 40.8% of parent survey respondents indicated that a lack of evening and weekend appointments is a barrier to

“Lack of evening and weekend appointments” was selected as a barrier to care by 40.8% of parent survey respondents.

care. At CSH specifically, a few assessment participants noted that certain services are available in some CSH locations but not others.

- **Suggestions for CSH:** Interviewees and survey respondents frequently noted that CSH should continue to expand the number of outpatient locations it has, as resources allow. In addition to increasing the number of outpatient locations, interviewees and survey respondents suggested expanding medical services, such as screenings and Applied Behavior Analysis, and recreational offerings, such as Friday Night Fever and swimming, to additional sites that are already in operation but do not currently have a full range of services.

Language Barriers

- **Barriers and Challenges:** Interviewees described particular challenges that non-English-speaking parents face when trying to self-identify developmental and behavioral concerns, advocate within pediatrician offices and schools, and coordinate care for their children across multiple providers. Language barriers were not raised by many survey respondents; however, it should be noted that the survey was distributed in English only.
- **Suggestions for CSH:** While CSH was described as being “progressive” in addressing language barriers, interviewees stated that more bilingual providers are needed, in addition to interpreters and language lines, which a few interviewees described as “impersonal”.

“[For] Latino children, children of immigrants, Spanish-speaking children... it’s hard for families to navigate referrals and make connections between places.” – Key informant interviewee

Navigating and Coordinating Care:

- **Barriers and Challenges:** A few interviewees described challenges that families face in navigating the health care system for children with special health care needs, including scheduling and tracking multiple appointments and obtaining insurance referrals. Care navigation was described as being particularly difficult for parents who do not speak English and/or have low levels of health literacy. A few interviewees also stated that parents or caregivers often become responsible for coordinating care between multiple providers, which can be burdensome. However, only 8.1% of survey respondents indicated that “*lack of communication among child(ren)’s provider(s)/ care team(s)*” was a barrier to care.
- **Suggestions for CSH:** Some interviewees suggested that CSH use patient navigators or care coordinators, and/or consider expanding its family-centered medical home. Survey respondents also indicated ways in which technology may be used to navigate and coordinate care, including using technology to contact providers directly, fill prescriptions, access medical records and progress reports, track medications, schedule appointments, and view bills and test results.

Community Awareness of Special Needs and Children’s Specialized Hospital

- **Barriers and Challenges:** While pediatricians and schools may refer children to CSH, parents can also recognize a need and seek out CSH directly. Some interviewees perceived a need for greater awareness of CSH in the community at large. Survey respondents, however, were not asked to comment on community awareness.
- **Suggestions for CSH:** A few interviewees suggested that CSH work to increase awareness of special needs and CSH’s services in the community at large. Interviewees also noted that targeted outreach to certain communities, such as the Latino community and the South Asian community, is important to reach populations that may be less likely to seek out services. A few interview participants also noted that CSH could build relationships with community organizations such as YMCAs, community centers, and churches and other religious spaces.

Community Physician Screening Practices and Awareness of Children’s Specialized Hospital

- **Barriers and Challenges:** Many interview participants stated that community physicians can play an important role in identifying children with special health care needs. However, interviewees noted that pediatricians are often pressed for time and so cannot proactively identify developmental and behavioral health issues. Additionally, a few interviewees stated that community physicians may not be aware of the services that CSH offers. Survey respondents were not asked specifically about pediatricians.
- **Suggestions for CSH:** Some interviewees suggested that more marketing could be done directly to community physicians to ensure that they are aware of CSH’s services. Some interviewees also stated that more could be done to educate community physicians around identifying and managing patients with developmental delays and behavioral health issues, and to support physicians through informal mechanisms (e.g., “office hours”) or formal partnerships.

Coordination between the Medical System and the Education System

- **Barriers and Challenges:** A majority of interviewees noted that, because there is no formal structure or process for medical and educational providers to communicate, parents are left to coordinate and advocate across systems (which can be particularly challenging for parents who do not speak English). Many survey respondents also described challenges understanding and navigating the special education system, and particularly Individualized Education Plans.
- **Suggestions for CSH:** Resources for navigating the special education system and working across both the medical and school system were requested frequently by survey respondents. Many key informant interviewees also expressed a need for increased communication between medical providers and school systems, while also acknowledging that time and resources are limited within both the health care and the education systems.

“[We need] resources for understanding how to connect the school to the doctors.”
– Survey respondent

Vision for the Future of Care for Children with Special Health Care Needs and Their Families

- Parent survey respondents were asked to rate priorities for how future resources and funding should be allocated. Increasing outpatient services (69.0%) and offering more programs that focus on social, emotional and other mental health issues for children with special health care needs (67.8%) were rated as “high priority” by a majority of survey respondents.

Impact of Actions Taken Since 2013 Assessment

CSH has developed plans and programs to address needs identified in its 2013 assessment. The 2016 assessment has also refined some 2013 needs, such as identifying a need for greater awareness of CSH services and programs among additional audiences beyond those specified in the 2013 assessment. A full description of 2013 needs and themes and CSH’s associated activities is included in Appendix D.

Prioritized Description of Identified Needs and Potential Resources to Address Needs

A description of priority needs and associated potential resources are presented below. A complete description of the prioritization process and criteria is included in the body of the full report below.

Description of Need: Assessment participants perceived a need for greater awareness of special health care needs, and also of CSH and the hospital’s services, in the community at large.

- *Potential Opportunities and Resources:* CSH could increase its marketing to existing patients about services such as recreational offerings, and may also consider further publicizing its

services to increase awareness in the community at large, targeting underserved and/or non-English-speaking populations in particular.

***Description of Need:* Assessment participants noted that community pediatricians may not have the time, expertise, and support to identify and manage patients with special needs.**

- *Potential Opportunities and Resources:* To support community physicians in identifying and managing patients with special needs, CSH may reach out directly to community practices to increase awareness of CSH's services and also offer advice and guidance.

***Description of Need:* A need for social and recreational services, in particular support groups and social skills groups for children with special health care needs and their siblings and parents, emerged as an overarching theme.**

- *Potential Opportunities and Resources:* CSH may consider expanding opportunities for children with special health care needs to socialize and to be physically active. Support groups and educational workshops for caregivers and siblings may also be expanded, and virtual or online communities could be developed.

***Description of Need:* Challenges working with schools and ensuring that children with special health care needs receive the support they need was frequently raised as a concern by assessment participants.**

- *Potential Opportunities and Resources:* CSH may support parents in navigating the education system by promoting current parent workshops and providing additional resources on the development of Individualized Education Plans.

***Description of Need:* A need for expanded hours and locations, particularly for families of limited means, was raised frequently during the assessment.**

- *Potential Opportunities and Resources:* CSH could consider opening additional outpatient center locations, and also expanding existing medical and recreational services that are currently located at only a few centers to additional centers. CSH could also consider offering evening and weekend appointments, and expanding its telemedicine work.

***Description of Need:* A need for more pediatric mental health providers and more bilingual providers was an especially prominent theme in the assessment.**

- *Potential Opportunities and Resources:* If feasible given the supply of providers, CSH could augment its health care services for children with special health care needs by hiring more pediatric mental health providers and more bilingual providers. The hospital could also leverage its existing partnerships, for example with the Robert Wood Johnson Medical School, to offer dental and additional specialty care (e.g., gastroenterology) for children with special health care needs.

***Description of Need:* Assessment participants described a need for greater care coordination so that parents do not have to coordinate and communicate across multiple providers and systems.**

- *Potential Opportunities and Resources:* CSH may explore models for supporting families around care coordination, such as employing patient navigators and care coordinators and/or expanding its family-centered medical home. CSH may also be able to leverage its patient portal in helping families navigate and coordinate care.

BACKGROUND

Overview of Children’s Specialized Hospital

Children’s Specialized Hospital (CSH) is a 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 to developmental and behavioral issues. The mission of Children's Specialized Hospital is to be the preeminent provider of specialized healthcare services for infants, children and young adults. CSH has 13 different New Jersey locations, and is an affiliate member of the Robert Wood Johnson Health System. As a leader in providing pediatric physician services to children with special healthcare needs, CSH employs pediatric physicians that specialize in pediatric primary care, developmental behavioral pediatrics, neurology, orthopedics, physiatry, and psychiatry.

Purpose and Goals of the Assessment

In December 2015, CSH contracted with Health Resources in Action (HRiA), a non-profit public health organization in Boston, to conduct a community health needs assessment. This report describes the process and findings from this effort. The assessment process was undertaken to achieve the following overarching goals:

- To determine perceptions of the health-related needs of children with special health care needs and their families
- To build upon CSH’s 2013 assessment and identify current barriers to accessing health care, as well as gaps and challenges in care, for children with special health care needs and their families
- To explore opportunities for addressing identified needs and filling gaps

Summary of 2013 Children’s Specialized Hospital Assessment

In 2013, CSH conducted an assessment to learn more about the health status of the communities served by CSH, to evaluate service utilization patterns, and to identify gaps in services and potential high-quality, cost-effective strategies to fill these gaps. To gather data for this assessment, secondary data was reviewed, four key informant interviews and two focus groups were conducted, and two surveys were distributed to educators and referring clinicians. Needs identified in this 2013 assessment included: (1) a need for greater visibility and education at the state level regarding the services and programs offered by CSH; (2) a need for increased communication between health plans and providers; (3) a need for the mental health network to be prevention-based and to participate in managed care; and (4) a need for the development of a succession plan to ensure ongoing and consistent growth. This 2016 assessment builds upon the 2013 assessment by examining progress made since 2013; exploring current gaps and challenges related to awareness, communication, and mental health services; and identifying new and emerging needs of children with special health care needs and their families.

Definition of Community Served for 2016 Children’s Specialized Hospital Assessment

This community health needs assessment focuses on the needs of children with special health care needs and their families residing in the state of New Jersey. CSH has 13 locations in 9 of New Jersey’s 21 counties. This assessment examines needs across the State; however, particular attention was given to at-risk populations, including racial/ethnicity minority groups and low-income residents. Given that quantitative data were often not available by these specific sub-groups, the key informants were carefully selected to provide these perspectives. Additionally, given that CSH serves some families from outside the state, quantitative state-level data was compared to national indicators, and eligibility for the parent survey (see below for more information) was not restricted by state of residence.

METHODS

The following section describes how data for the community health needs assessment was compiled and analyzed. A mixed-methods approach was used, which included a thorough review of existing secondary data, interviews with key stakeholders at CSH and in the community, and an online survey with parents. In total, over 300 individuals provided input as part of this assessment. Combined, these data sources aim to provide insight into the needs of children with special health care needs and their families including: barriers to accessing care, particularly for vulnerable populations; gaps in and challenges with existing health care services for children with special health care needs and their families; and possible solutions to address challenges and fill gaps. This section provides a more detailed description of the data collection methods used in this assessment.

Quantitative Data

The following section describes the quantitative data sources included in this report.

Review of Secondary Data

In an effort to develop a social, economic, and health portrait of children with special health care needs and their families, HRIa reviewed existing data drawn from national sources. Sources of data included the U.S. Census Bureau, the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the U.S. Department of Education, among others. Data analyses were generally conducted by the original data source (e.g., U.S. Census, Health Resources and Services Administration). Types of data included self-report of health behaviors from large, population-based surveys such as the Youth Risk Behavior Surveillance System (YRBSS), as well as vital statistics.

Parent Survey

In order to understand parents' perceptions of access to services, gaps in services, and priorities for future programming and initiatives, a brief survey was developed and administered online to a listserv comprised of parents of children who had ever received care at CSH, as well as key community stakeholders such as advocates and policy analysts. The survey included an automatic skip pattern where parents and non-parents were taken to separate sets of questions tailored to their perspectives. CSH reviewed and provided feedback on the survey and also disseminated the survey link to this listserv; the listserv had 10,410 members during the date of the first distribution of the survey link, and 16,608 members during the reminder distribution of the survey link (the listserv membership was updated between the two distribution dates). The survey was administered for three weeks, from January 15, 2016 through February 5, 2016.

A total of 294 parents completed the survey (Appendix B contains quantitative data for all parent survey questions). A total of 7 non-parents completed the survey; these non-parent respondents were excluded from analysis as there were too few respondents to be able to draw meaningful conclusions about the perceptions of non-parent stakeholders. The perceptions of non-parent stakeholders were gathered through the key informant interviews (see below for more information). Table 1 presents the distribution of characteristics among all parent survey respondents. A majority of the survey respondents were female (92.3%) and survey respondents primarily spoke English at home (93.1%). Most respondents self-identified as Caucasian or White, non-Hispanic (61.8%), while 20.6% of survey respondents self-identified as Hispanic or Latino (Table 1).

Table 1: Children’s Specialized Hospital Needs Assessment Parent Survey Respondent Characteristics by All Respondents

| Characteristics (N=294) | Percent |
|---|---------|
| Gender | |
| Male | 6.2% |
| Female | 92.3% |
| Transgender | 0.4% |
| Other | 1.2% |
| Race/Ethnicity | |
| Caucasian/ White, non-Hispanic | 61.8% |
| African American/ Black, non-Hispanic | 9.5% |
| Hispanic/ Latino(a), any race | 20.6% |
| Asian/ Pacific Islander, non-Hispanic | 3.1% |
| Other* | 5.0% |
| Age** | |
| 18-34 years old | 22.2% |
| 35-44 years old | 44.4% |
| 45-64 years old | 33.3% |
| Highest Level of Education Completed | |
| High school graduate/GED or less | 16.2% |
| Some college or 2-year degree | 28.8% |
| 4-year college graduate | 27.3% |
| More than 4-year college degree | 27.7% |
| Primary Language Spoken at Home | |
| English | 93.1% |
| Spanish | 3.5% |
| Chinese | 0.8% |
| Hindi | 0.4% |
| Portuguese | 0.8% |
| Other | 1.5% |

* includes other race, non-Hispanic and two or more races, non-Hispanic

** does not include one under 18 year old respondent and one 65 years old or more respondent

Qualitative Data

The following section describes the qualitative data sources included in this report.

Key Informant Interviews

From January – April 2016, interviews were conducted with key stakeholders to gauge their perceptions of existing health care services for children with special health care needs and their families, to identify barriers, gaps and challenges in accessing and utilizing services, and to gather suggestions for programming, services, or initiatives that are most needed to address the identified concerns. A semi-structured moderator’s guide was used across all discussions to ensure consistency in the topics covered. Each interview was conducted by a trained researcher, and detailed notes were taken during conversations. On average, interviews lasted approximately 30 minutes.

Priority sectors and representative participants were identified by CSH. A total of eleven key informant interviews were conducted by phone with key stakeholders including CSH clinicians, board members and family advisors, as well as a community physician, a researcher, and representatives from the education, public health, and payer sectors (see Appendix A). Two of the interviewees had direct experience working with Spanish-speaking populations.

Parent Survey

The parent survey described above included open-ended questions asking respondents for input on additional types of medical, behavioral, and recreational services for children with special health care needs that could be made available; suggestions for services or workshops for parents, caregivers and/or siblings of children with special health care needs; and feedback on ways technology can support the care of children with special health care needs and their families. Appendix C contains all open-ended question responses, organized by theme.

Analyses

The collected qualitative data were coded and analyzed thematically, where data analysts identified key themes that emerged across all groups and interviews. Frequency and intensity of discussions on a specific topic were key indicators used for extracting main themes. Selected quotes – without personal identifying information – are presented in the narrative of this report to further illustrate points within topic areas.

Limitations

As with all research efforts, there are several limitations related to this assessment's research methods that should be acknowledged. There is a time lag for many large data surveillance systems such as Youth Risk Behavior Surveillance System (YRBSS), so data are not necessarily current for many indicators.

Data based on self-reports should be interpreted with particular caution. In some instances, respondents may over- or underreport behaviors and illnesses based on fear of social stigma or misunderstanding the question being asked. In addition, respondents may be prone to recall bias—that is, they may attempt to answer accurately but remember incorrectly. It is also important to note that the CSH needs assessment parent survey may be prone to selection bias – that is, individuals who had more positive or negative experiences may have been more likely than other individuals to complete the survey, so that survey respondents are not representative of the larger patient population. Therefore, the survey findings represent a sub-set of parents and may be limited in their generalizability. Despite these limitations, the self-report parent survey analyzed in this community health needs assessment benefit from a large sample size.

While the interviews conducted for this assessment provide valuable insights, results are not statistically representative of a larger population due to non-random recruiting techniques and a small sample size. Lastly, it is important to note that data were collected at one point in time, so findings, while directional and descriptive, should not be interpreted as definitive.

FINDINGS

PRESENTATION OF FINDINGS

The following sections present findings from the quantitative and qualitative data analyses. While the assessment focused on needs of children with special health care needs and their families broadly, survey respondents and key informant interviewees were also asked for suggestions around how CSH could potentially address the identified needs. Themes and findings related to needs are presented by section below; if assessment respondents offered any suggestions for how CSH could address needs, those suggestions are presented at the end of the relevant section.

SOCIAL AND ECONOMIC CONTEXT OF THE REGION

The health of a population is associated with numerous factors including what resources and services are available as well as who lives in the community. While CSH draws patients from across the region and the country, CSH's facilities are located in the state of New Jersey. The section below provides an overview of the population of New Jersey.

Demographics

CSH has 13 locations in 9 counties in New Jersey. As illustrated in Table 2, the total population of the counties in which CSH facilities are located range in size from 275,325 (Atlantic County) to 824,046 (Middlesex County).

Table 2: Total Population, State and County, 2010-2014

| Geography | Population |
|-------------------|------------|
| New Jersey | 8,874,374 |
| Atlantic County* | 275,325 |
| Bergen County | 920,456 |
| Burlington County | 450,155 |
| Camden County | 512,632 |
| Cape May County | 96,286 |
| Cumberland County | 157,429 |
| Essex County* | 789,616 |
| Gloucester County | 289,705 |
| Hudson County* | 654,878 |
| Hunterdon County | 126,746 |
| Mercer County* | 369,526 |
| Middlesex County* | 824,046 |
| Monmouth County | 629,702 |
| Morris County | 497,103 |
| Ocean County* | 581,413 |
| Passaic County* | 505,403 |
| Salem County | 65,501 |
| Somerset County* | 328,704 |
| Sussex County | 146,888 |
| Union County* | 545,236 |
| Warren County | 107,624 |

*County in which a CSH facility is located

DATA SOURCE: US Department of Commerce, Bureau of the Census, American FactFinder, 2010 - 2014 American Community Survey

Table 3 shows the racial and ethnic distribution of New Jersey as a whole and by County. A majority of residents in New Jersey self-identify as white, non-Hispanic (57.8%), followed by residents who self-identify as Hispanic (17.7%) and Black, non-Hispanic (14.7%). Among the nine counties in which CSH facilities are located, Ocean County has the highest percentage of residents who self-identify as White, non-Hispanic (85.4%); Essex County has the highest percentage of residents who self-identify as Black, non-Hispanic (39.0%); Hudson County has the highest percentage of residents who self-identify as Hispanic (42.7%), and Middlesex County has the highest percentage of residents who self-identify as Asian, non-Hispanic (22.8%).

Table 3: Racial/Ethnic Distribution, State and County, 2010-2014

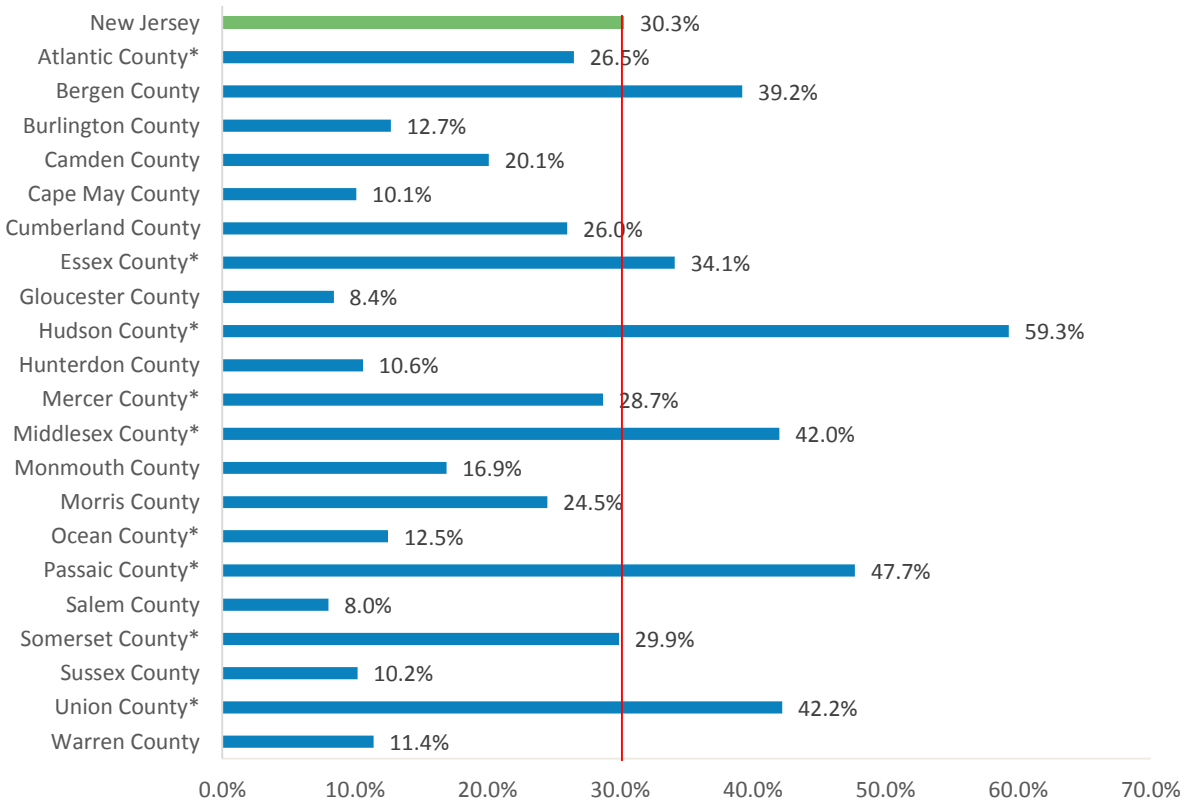
| Geography | White, non-Hispanic | Black, non-Hispanic | Hispanic, any race | Asian, non-Hispanic | Other, non-Hispanic |
|-------------------|----------------------------|----------------------------|---------------------------|----------------------------|----------------------------|
| New Jersey | 57.8% | 12.8% | 18.6% | 8.7% | 2.0% |
| Atlantic County* | 57.5% | 14.7% | 17.7% | 8.0% | 2.1% |
| Bergen County | 60.3% | 5.3% | 17.4% | 15.1% | 1.8% |
| Burlington County | 69.5% | 15.7% | 7.1% | 4.5% | 3.2% |
| Camden County | 59.1% | 18.2% | 15.0% | 5.4% | 2.3% |
| Cape May County | 86.3% | 4.4% | 6.8% | 1.1% | 1.4% |
| Cumberland County | 49.0% | 19.0% | 28.2% | 1.3% | 2.6% |
| Essex County* | 32.4% | 39.0% | 21.3% | 4.8% | 2.5% |
| Gloucester County | 80.0% | 9.9% | 5.2% | 2.8% | 1.9% |
| Hudson County* | 29.6% | 11.2% | 42.7% | 14.1% | 2.3% |
| Hunterdon County | 87.3% | 2.4% | 5.7% | 3.5% | 1.2% |
| Mercer County* | 52.9% | 19.6% | 15.9% | 9.6% | 2.0% |
| Middlesex County* | 47.0% | 9.0% | 19.2% | 22.8% | 2.0% |
| Monmouth County | 76.2% | 6.7% | 10.1% | 5.2% | 1.7% |
| Morris County | 73.5% | 3.0% | 12.2% | 9.4% | 2.0% |
| Ocean County* | 85.4% | 2.9% | 8.6% | 1.8% | 1.2% |
| Passaic County* | 43.9% | 11.1% | 38.4% | 5.1% | 1.4% |
| Salem County | 76.0% | 13.8% | 7.5% | 0.9% | 1.8% |
| Somerset County* | 60.3% | 8.7% | 13.7% | 15.2% | 2.2% |
| Sussex County | 88.1% | 1.9% | 6.9% | 1.8% | 1.4% |
| Union County* | 43.2% | 20.4% | 28.8% | 4.7% | 2.9% |
| Warren County | 84.3% | 4.0% | 7.7% | 2.6% | 1.4% |

*County in which a CSH facility is located

DATA SOURCE: US Department of Commerce, Bureau of the Census, American FactFinder, 2010 - 2014 American Community Survey

Figure 1 illustrates that 30.3% of the population in New Jersey speak a language other than English at home. Among the nine counties in which CSH facilities are located, the percent of the population speaking a language other than English at home ranges from 26.5% (Atlantic County) to 59.3% (Hudson County).

Figure 1: Percent Population Over 5 Years of Age Who Speak a Language Other Than English at Home, State and County, 2010-2014

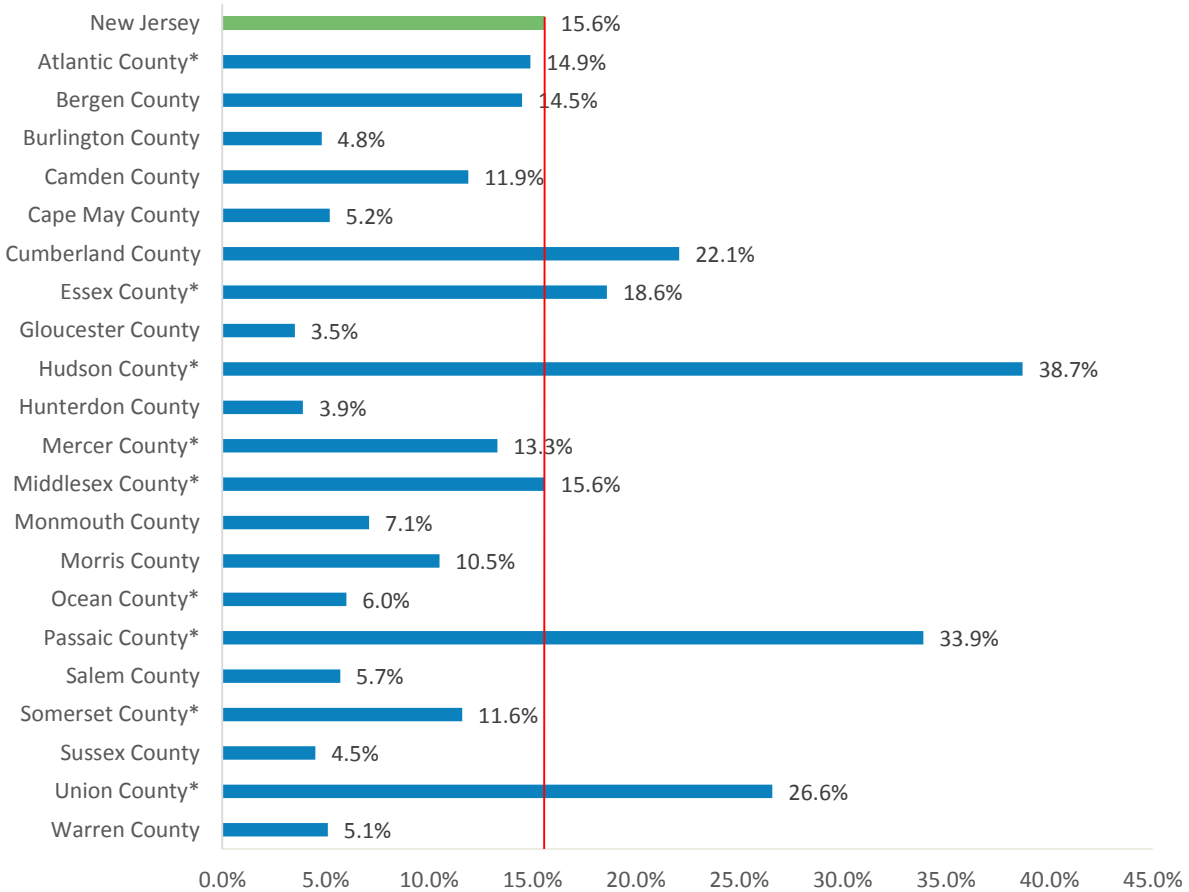


*County in which a CSH facility is located

DATA SOURCE: US Department of Commerce, Bureau of the Census, American FactFinder, 2010 - 2014 American Community Survey

In New Jersey, 15.6% of the population overall speak Spanish at home (Figure 2). In five (Essex, Hudson, Middlesex, Passaic, Union) of nine counties in which CSH facilitate are located, an equal or higher percentage of the population speaks Spanish at home, compared to the state of New Jersey (Figure 2).

Figure 2: Percent Population Over 5 Years of Age Who Speak Spanish at Home, State and County, 2010-2014



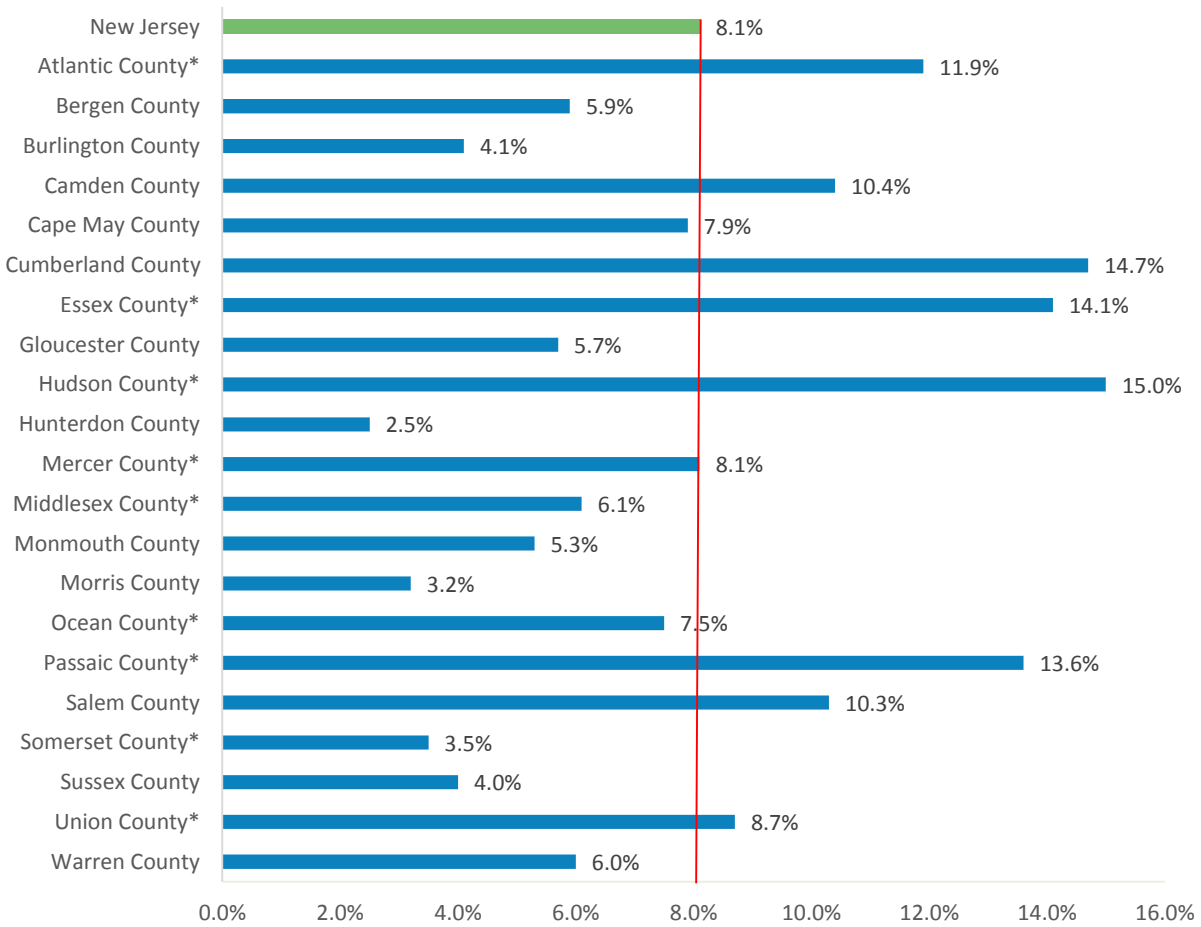
*County in which a CSH facility is located

DATA SOURCE: US Department of Commerce, Bureau of the Census, American FactFinder, 2010 - 2014 American Community Survey

Poverty Status and Education

A family's income level impacts their access to health care, as well as their access to related necessities and resources such as transportation, healthy food, and recreational opportunities. Figure 3 illustrates that, overall, 8.1% of families in New Jersey live below the poverty line. In six out of the nine counties in which CSH facilities are located, the percentage of families living below the poverty line is equal to or higher than the percentage of families living below the poverty line in New Jersey (8.1%, Figure 3).

Figure 3: Percent Families Living Below Poverty Level, State and County, 2010-2014

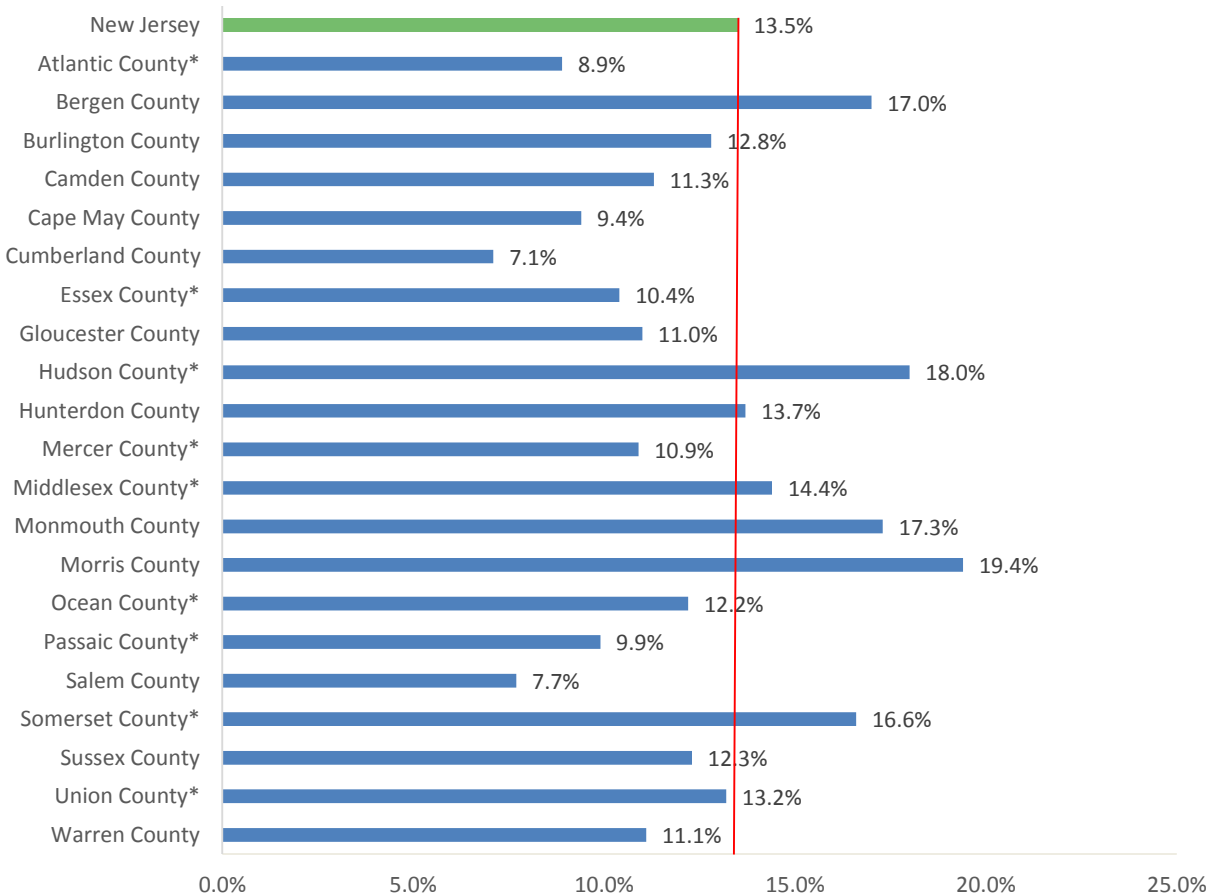


*County in which a CSH facility is located

DATA SOURCE: US Department of Commerce, Bureau of the Census, American FactFinder, 2010 - 2014 American Community Survey

Parents' education level can impact access to employment and other resources. As illustrated in Figure 4, 13.5% of adults age 25 years and old in New Jersey have obtained at least a Bachelor's degree. The percentage of adults with a Bachelor's degree or higher is lower than in New Jersey in 6 out of the 9 counties in which CSH facilities are located (this percentage is only higher in Hudson, Middlesex, and Somerset Counties, Figure 4).

Figure 4: Percent of Adults 25 Years and Older with a Bachelor's Degree or Higher, 2010-2014



*County in which a CSH facility is located

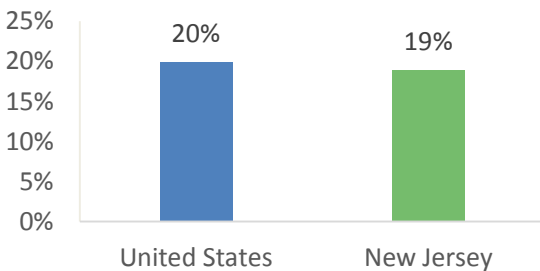
DATA SOURCE: US Department of Commerce, Bureau of the Census, American FactFinder, 2010 - 2014 American Community Survey

POPULATION OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN NEW JERSEY

Children’s Specialized Hospital is a national provider of inpatient and outpatient care for children with special health care needs. To lay a foundation for the assessment and provide critical information on the magnitude of key issues for children with special health care needs and their families, available secondary data is presented below.

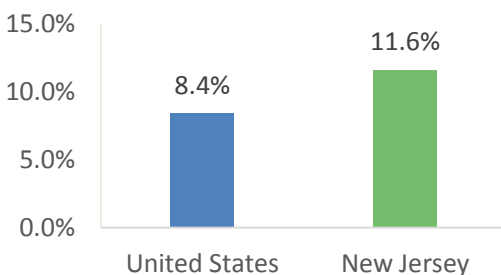
The National Survey of Children with Special Health Care Needs defines Children with Special Health Care Needs as “children under age 18 who are at increased risk of a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.” As of 2011/2012, 20% of children under age 18 in the U.S. overall and 19% of children under age 18 in New Jersey met this definition of having special health care needs (Figure 5). However, in 2013, a higher percentage of students aged 6 to 21 received special education services in New Jersey (11.6%) compared to the U.S. overall (8.4%) (Figure 6).

Figure 5: Percent Children With Special Health Care Needs, by United States and New Jersey, 2011-2012



DATA SOURCE: National Survey of Children with Special Health Care Needs/ National Survey of Children's Health, 2011 – 2012, Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, as cited by Kids Count

Figure 6: Percent Special Education Students Aged 6 to 21 Years Served under Individuals with Disabilities Education Act (IDEA) Part B, by United States and New Jersey 2013

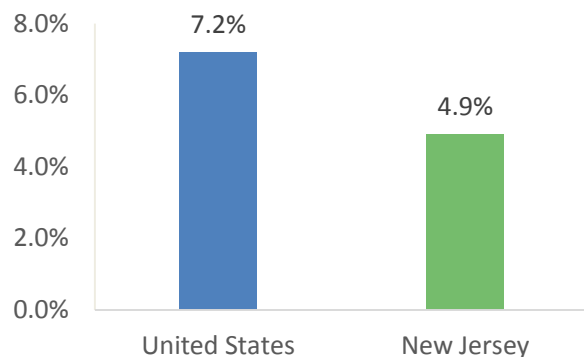


DATA SOURCE: U.S. Department of Education, IDEA Section 618 Data Products, Fall 2013 Individuals with Disabilities Education Act Part B Child Count and Educational Environments as cited by Annual Disability Statistics Compendium

Limited up-to-date data is available for specific diagnoses relevant to children with special health care needs. As of the most recent National Survey of Children's Health, rates of ADD/ADHD among children aged 2 to 17 in New Jersey (4.9%) were lower than in the U.S. overall (7.2%) (Figure 7). Similarly, the percent of high school youth who felt sad or hopeless every day for 2 or more weeks in the past 12 months is slightly lower in New Jersey (28.7%) compared to the U.S. overall (29.9%) (Figure 8). However,

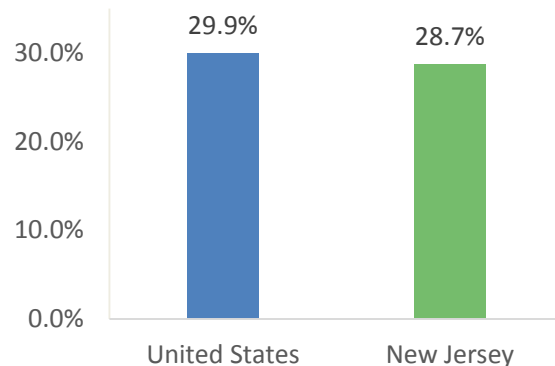
in 2010, the most recent year for which data is available, rates of autism among 8-year-old children in New Jersey were higher (22.2 per 1,000 children) compared to the U.S. overall (14.7 per 1,000 children) (Figure 9). Between 2008 and 2010, rates of autism rose in both New Jersey and the U.S., and the rate increased by a greater amount in the U.S. overall (Figure 9).

Figure 7: Percent Children Aged 2 to 17 Years Reported to Have ADD/ADHD, by United States and New Jersey, 2011-2012*



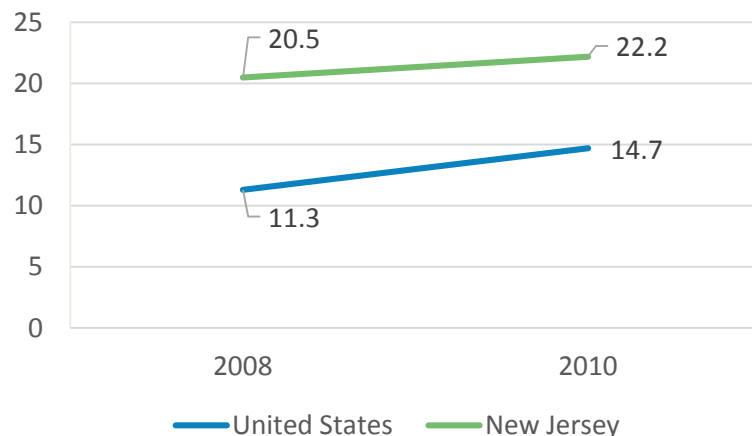
*DATA SOURCE: 2011-2012 National Survey of Children's Health, Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health, as cited on www.childhealthdata.org, 2015

Figure 8: Percent High School Youth Reported to Have Felt Sad or Hopeless in Past 12 Months, by United States and New Jersey, 2013**



** DATA SOURCE: Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance System, High School Youth Risk Behavior Survey, 2013
NOTE: felt sad or hopeless for almost every day for 2 or more weeks in a row so that they stopped doing some usual activities

Figure 9: Rate of Children Diagnosed With Autism Spectrum Disorder per 1,000 Children, by United States and New Jersey, 2008 – 2010



DATA SOURCE: Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years, Autism and Developmental Disabilities Monitoring Network, CDC, 2010, as cited in Community Report from the Autism and Developmental Disabilities Monitoring Network, 2014 and Centers for Disease Control and Prevention (CDC). Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2008. Morbidity and Mortal Weekly Report (MMWR) 2012; Vol. 61(3).

PERCEPTIONS OF EXISTING SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

This section focuses on perceptions of existing services for children with special health care needs and their families in general, and also on perceptions of services at CSH specifically.

General Perceptions of Existing Health Care Services for Children with Special Health Care Needs

“Scattered. Meaning that services are out there, but a unified way of finding those services is extremely difficult.” – Key informant interviewee

“[There is] huge variation based on geography, type of insurance, immigration status, and other things that are more traditionally associated with health disparities – like poverty, housing, race, and language spoken at home.” – Key informant interviewee

When asked to describe the existing health care services for children with special health care needs and their families, a majority of key informant interviewees described a fragmented health care system that can be challenging for families to navigate. Interviewees also acknowledged that the services and resources available to children with special health care needs and their families can vary greatly depending on their insurance coverage, socioeconomic status, immigration status, and language spoken at home.

Some interviewees also discussed the context of care for children with special health care needs within that state of New Jersey. One interviewee stated that the early intervention system in the state of New Jersey is robust, and “goes beyond” what is required by federal law. However, a few interviewees noted that Medicaid reimbursement for providers in New Jersey is very low, limiting the supply of providers who accept children with special health care needs with Medicaid insurance.

Perceptions of Children’s Specialized Hospital

“We recommended this hospital to so many, because of the friendliness and great professionalism.... the overall feel [our] boys had was not of being scared but at ease.” – Survey respondent

“They understand that it spans not just the medical but also the educational and the social. It took us a while to find the right place, and find a place that has the thoughtfulness. I fell in love with Children’s Specialized Hospital and so many of the providers individually. They provide not just services but also their care.” – Key informant interviewee

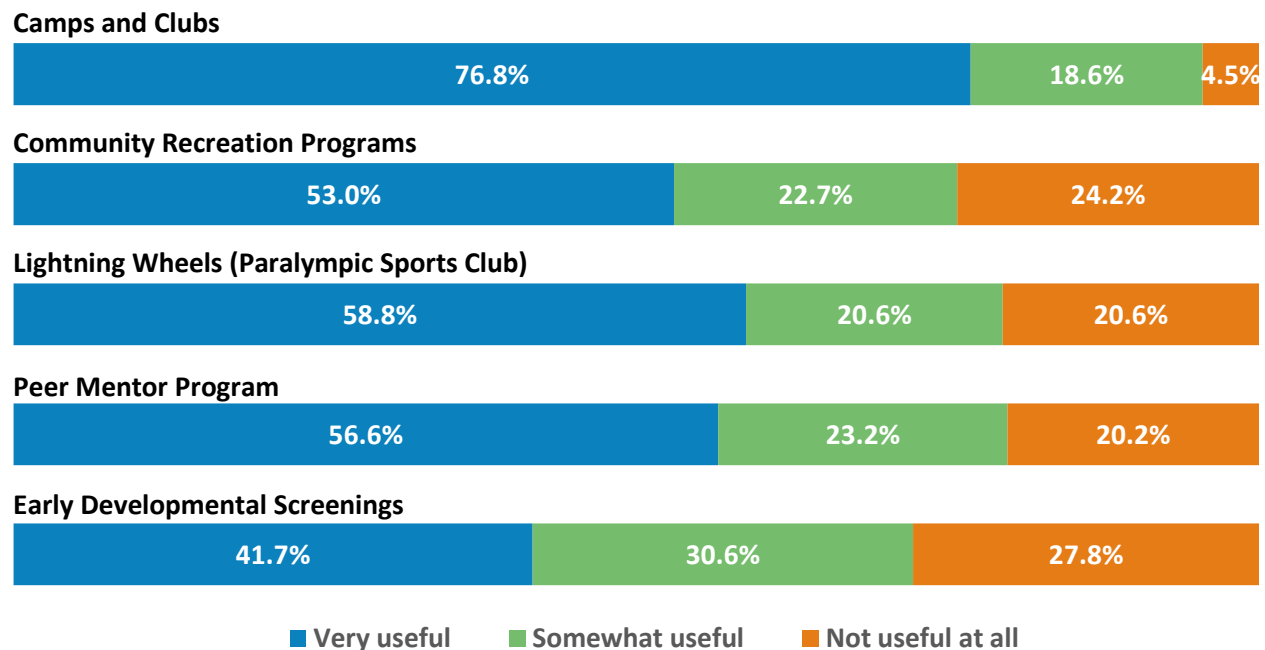
CSH was described as an institution that provides high quality services and truly cares about the patients it serves and their families. The care that CSH provides was described as “extraordinary” and “amazing,” and many interviewees and survey respondents noted that CSH’s staff, including high-level administrators and direct health care providers, are thoughtful and caring. Interviewees also recognized CSH for focusing on underserved populations. A few interviewees praised CSH’s expansion of outpatient services throughout the state and noted that this expansion has relieved the burden on some families who now do not have to travel as far to access services.

CSH was also frequently described as an innovator, a leader, and, in the words of one interviewee, a “really progressive institution.” In particular, CSH was seen as leading efforts to develop a medical home

model, and was recognized for their family-centered medical home which provides primary care to children with special health care needs and their siblings. One interviewee also noted that CSH has been exploring ways to use advanced practice nurses to deliver services and expand access to diagnostic services. A few interviewees also stated that CSH has been adept at exploring new technology, such as telemedicine.

When asked about specific Specialty Programs at CSH in the assessment survey, the majority of the survey respondents rated all the specialty programs as “very useful” or “somewhat useful” (Figure 10). Camps and clubs were rated “very useful” by the majority of respondents (76.8%), whereas early developmental screenings were rated “not useful at all” by only 27.8% of respondents.

Figure 10: Perceived Usefulness of Specialty Programs, 2016



DATA SOURCE: Children’s Specialized Hospital Community Health Needs Assessment Survey, 2016
 NOTE: Camps and Clubs include Camp Chatterbox, BECOME Program, Pal’s Paradise, Camp Kresge; Community Recreation Programs include Martial Arts Program, Adaptive Aquatics Program, Friday Night Fever

Despite this generally positive perception of CSH’s services and leadership, assessment participants did identify some barriers to accessing care at CSH and some gaps in services. These barriers, gaps, and related challenges are discussed further below.

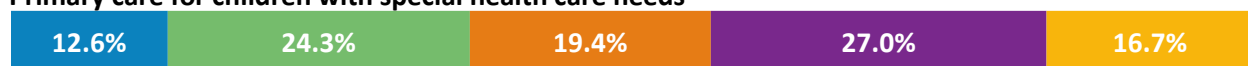
GAPS IN EXISTING SERVICES AND SERVICE SUGGESTIONS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

This section describes gaps in existing services for children with special health care needs and their families. Gaps are presented broadly, considering services that are generally available in the community for children with special health care needs and their families. If a gap is specific to CSH, it is noted. After each gap, suggestions for additional programs and services that CSH could develop to fill gaps are presented.

In the assessment survey, respondents rated the ease of accessing a variety of specific services (Figure 11). Nearly half of respondents (48.6%) reported that specialty care was “hard” or “very hard” to access and 43.7% of respondents found it “hard” or “very hard” to access primary care for children with special health care needs (Figure 11).

Figure 11: Perceived Ease of Access to Services for Child with Special Health Care Needs, 2016

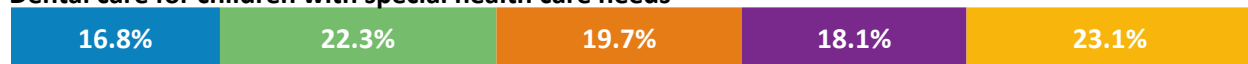
Primary care for children with special health care needs



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 and services for children with special health care needs



Educational programs and services for children with special health care needs



■ Very easy ■ Easy ■ Not easy or hard ■ Hard ■ Very hard

DATA SOURCE: Children’s Specialized Hospital Community Health Needs Assessment Survey, 2016

Medical and Behavioral Health Services

Gaps:

“I don’t think that you need any additional services, just additional service providers so that the waiting lists are not as long.” – Survey respondent

“We have a lot of providers in the state of New Jersey, but there are not as many providers as there are families looking for [developmental] evaluation services... You don’t want to wait 8

months for an evaluation when your kid is 2. That's a third of [the child's] life!" – Key informant interviewee

"Access to psychology services is always a challenge and to mental health services more broadly. There are simply not enough child psychologists and psychiatrists to be able to serve the need." – Key informant interviewee

Interview and survey respondents frequently noted that, due to a limited supply of certain types of providers in the community, there can be long wait times for appointments. Survey respondents frequently noted that CSH already offers the services their families need, but noted that more providers are needed so that the wait times for appointments can be shorter. "Long wait times to schedule appointments" was a top barrier selected by 40.8% of parent survey respondents (see Figure 12 below).

Behavioral/mental health care was rated "hard" or "very hard" to access by about a third of survey respondents (35.7%) (Figure 11). In particular, survey and interview respondents frequently stated that more pediatric mental health providers, including therapists, psychologists, psychiatrists, and developmental pediatricians, as well as neurologists are needed. Because of a shortage in behavioral health providers, interviewees noted that families face long wait times for appointments, which can be discouraging and nerve-wracking.

Dental care was rated "hard" or "very hard" to access by 41.2% of survey respondents (Figure 11). Some survey respondents noted a need for access to dental care for CSH. While primary care was rated "hard" or "very hard" to access by 43.7% of survey respondents (Figure 11), it was not mentioned frequently among the open-ended survey responses or during the interviews. Specialty care was rated "hard" or "very hard" to access by almost 50% of survey respondents (Figure 11), some of whom noted that access to gastroenterologists and endocrinologists in particular is needed. A few interviewees also noted that it is difficult to find certain types of tertiary care for children with special health care needs in New Jersey, such as gastroenterology and oncology. Interviewees stated that some families must travel out of state to access these types of specialty care, which can create transportation challenges and can impose costs for hotel accommodations.

Suggestions for CSH:

"[Children's Specialized Hospital] should have ABA [Applied Behavior Analysis] services in each location to make it convenient for parents." – Survey respondent

"I think CSH and the children could benefit greatly from an on-site dental program. I hear many, many parents struggle with not only finding a provider who accepts their insurance, but also one who is experienced in the special needs our kids require." – Survey respondent

Parent survey respondents were asked what additional types of medical and behavioral health services CSH should offer. A need for more behavioral health personnel, particularly to lessen wait times for appointments, was noted by many survey respondents. Many survey respondents and some interviewees noted that there is a need for more Applied Behavior Analysis (ABA) providers at more CSH locations, such as Hamilton and Clifton, and a few interviewees also stated that providers who are trained in cognitive behavioral therapy and anxiety treatment are needed. Many key informant interviewees also noted that there is a need for more pediatric mental health providers who accept Medicaid.

In addition to mental health providers, a few interviewees and some survey respondents noted that there is a need for more pediatric sub-specialists that provide particular types of care such as pediatric gastroenterology and oncology. However, one interviewee noted that, because there are so few pediatric sub-specialists, these sub-specialists can charge high rates or do not participate in insurance plans (e.g., families pay out of pocket). While interviewees stressed the need for more mental health and sub-specialist providers, they also acknowledged that this is a “manpower issue” that cannot be solved quickly. A few interviewees noted that CSH may want to partner with other hospitals for services not available at CSH. Lastly, as described above, although dental care was not raised during the interviews, some survey respondents suggested that CSH consider providing dental care.

Social and Recreational Programs and Services

Gaps:

“I am not aware of the recreational programs and services available at Children's Specialized Hospital. Perhaps my best advice would be to make your programs known to parents who bring their children to Children's Specialized Hospital.” – Survey respondent

“In our area, there is a high population of children with autism... [But] there's so little for the general disabled population. It's definitely created a void for kids with cerebral palsy, traumatic brain injury, and other... general disabilities. They don't fit into the autism picture.” – Key informant interviewee

Recreational programs and services for children with special health care needs were rated “easy” or “very easy” to access by almost 50% of survey respondents (Figure 11). While overall these services were perceived as being relatively accessible, a few interviewees described the perception that many resources and services exist for children with autism, given that there is a high population of children who have been diagnosed with autism and that there is a strong local organization, Parents of Autistic Children (POAC). However, one interviewee stated that, in comparison, activities such as physical activity opportunities or social programs for children with other diagnoses seem quite limited.

Some parent survey respondents also stated that they were not aware that CSH offered recreational programs, and were interested in more information about available services. Others stated that the existing recreational programs should be expanded to different locations, as some families are unable to travel to locations that currently offer these services. Some survey respondents did also note that existing recreational services are adequate as is.

Suggestions for CSH:

“Social interaction groups among [peers]. Maybe even social groups based on the special needs of the kids. This may help them know that they aren't alone.” – Survey respondent

“Sports, musical, [gymnastics], since [it] is so hard for them to go into any regular ones!” – Survey respondent

Parent survey respondents were asked to describe any additional types of recreational programs and services that they thought should be offered by CSH. Survey respondents frequently stated that more sports and physical activity programs, including gymnastics, basketball, dance, lacrosse, swimming, yoga and biking-riding, should be offered. Additionally, many survey respondents stressed the need for more social skills groups, play groups, and peer support groups for children with special health care needs.

Parents also requested more camps, arts and crafts programs such as photography, and music programs. Some parents noted that organized outings, like group field trips, movie dates, zoo trips, beach trips, and trips to plays and concerts, would be beneficial. Some parents also identified the need for recreational services for children with specific diagnoses (e.g., ADHD, autism, fetal alcohol syndrome, and those with severe special needs), and for specific age groups (e.g., toddlers and pre-schools, tweens, and teens).

Support for Parents, Caregivers, and Siblings

Gaps:

“Support groups, classes, speakers and presentations on related topics.” – Survey respondent

“We need the process of sending a specialized nurse into the community to give families respite support. I don’t know how families do it... So families can go on vacation, go to a wedding. But Medicaid won’t pay for it.” – Key informant interviewee

Survey and interview respondents described a need for support groups and educational workshops for parents, caregivers, and siblings of children with special health care needs. Interviewees and a few survey respondents also noted a need for more respite care. Interviewees stated that some families deliver a “significant amount” of medical and nursing care to children at home. Interviewees described a need for these caregivers to have breaks from time-to-time, which could involve sending specialized nurses into the community or admitting children to an inpatient facility for a defined amount of time. However, interviewees stated that insurance does not commonly cover respite care. As one interviewee stated, *“if you have a kid that’s severely involved, has severe medical needs, we forget about you... your emotional needs are no longer even considered”*.

Despite the need for social, emotional, and education support, a few interviewees noted that, while there is a need for this type of family support, it can be challenging for families to find the time to participate in additional groups and activities given their reality, which can often be “unpredictable” and can vary day-to-day in how severe a child’s condition is and how well a family is coping. Thus, as one interviewee stated, parents and caregivers are acknowledging that they need support, *“but because of their reality they can’t always get it.”*

Suggestions for CSH:

“I have seen so many siblings of special needs children suffer from depression. They feel that they need to be more for their family to make up for their siblings shortcomings. They don’t want to be a burden. Attention needs to be given to these children to make sure that their mental health is in check.” – Survey respondent

“Behavioral and sensory classes for parents so that they may learn strategies and techniques to deal with issue that arise at home.” – Survey respondent

“Navigating the 504/IEP world at school, helping to know how to best advocate for your child’s needs in the educational setting.” – Survey respondent

Parent survey respondents were asked to describe specific types of services or workshops for parents, caregivers, and/or siblings that they would like to see offered by CSH. Survey respondents frequently stated that support groups for siblings are needed, as well as educational workshops to help siblings

understand diagnoses and how to interact and support their brother or sister. Support groups for parents, as well as workshops for parents to learn specific skills such as coping with behavioral issues and managing stress, were also mentioned. Some survey respondents noted that online communities could be helpful for parents who cannot attend in-person events. Some respondents also noted that recreational programs and outings to places like the beach and water parks could include both children with special health care needs and their siblings. Many survey respondents also requested support around how to work with and advocate for their children within school systems, and navigate individualized education plans (IEPs). Lastly, some survey respondents requested support around specific diagnoses (e.g., fetal alcohol syndrome, autism, multiple diagnoses, etc.) and for specific age groups (e.g., adolescents).

Transitioning to Community and Adult Care

Gaps:

“[Where we] struggle [is the] transition to adult health care. Finding ways that there can be an age-appropriate transfer to adult practitioners, and finding ways to stimulate the adult health care system to develop the kind of care that Children’s Specialized has.” – Key informant interviewee

“If you were a regular parent, you would find a dance school for your child. The disabled population isn’t prominent. It feels like it is at Children’s Specialized, but you leave the Children’s Specialized building and it’s not. You are alone.” – Key informant interviewee

A few interviewees and survey respondents noted that it is difficult to transition to adult health care, once patients are over the age of twenty-one. One interviewee and a few survey respondents also mentioned challenges related to finding activities and support after being discharged from CSH. As this interviewee explained, at CSH, families feel “safe” and supported. Once they are discharged, they need to find activities in the community that accommodate children with disabilities, and develop a new routine. However, interviewees noted that it can be difficult to identify these types of recreational and supportive activities in the community.

Suggestions for CSH:

“Assigning a Case Manager, Social Worker, [or] Patient Care Coordinator... to coordinate all medical care, community care, rec opportunities, guidance during transitional times.” – Survey respondent

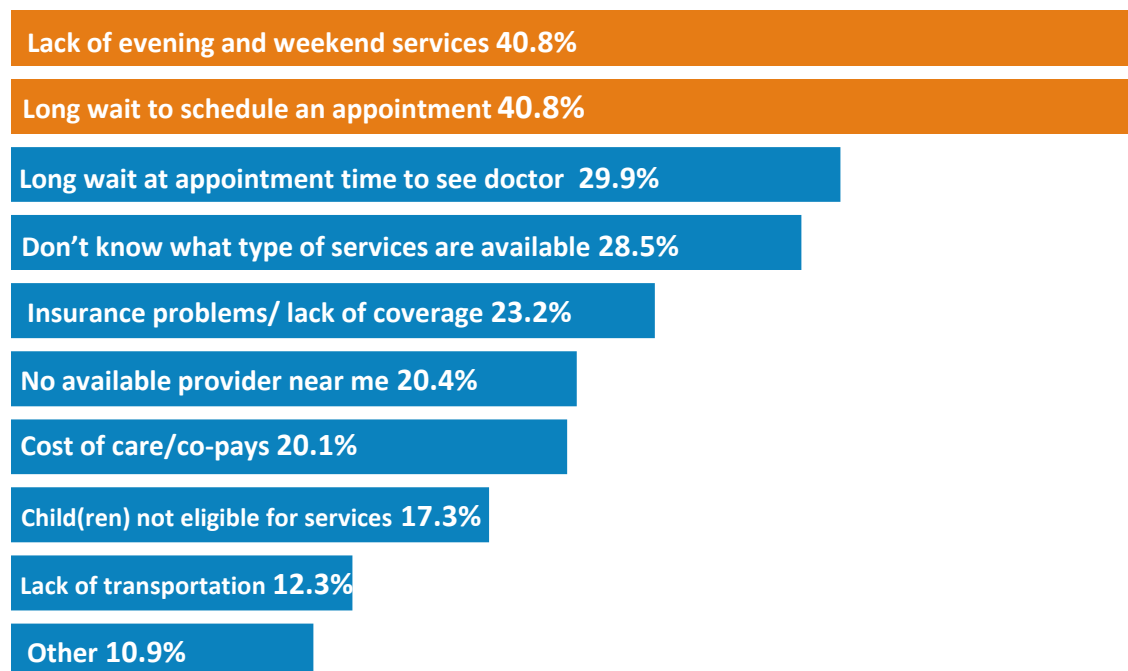
Assessment participants suggested that CSH could support families during transitions, and help facilitate connections with programs that provide care in the community and with adult providers. One interviewee noted that the Family Faculty may help facilitate connections with community programs, while a survey respondent suggested that a CSH social worker or case manager could help make these connections. Survey respondents and interviewees did note that the transition to adult care can be especially difficult, since the adult services that are available are sometimes quite limited, particularly for patients with Medicaid insurance.

BARRIERS AND CHALLENGES IN ACCESSING AND UTILIZING SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS, AND SUGGESTIONS FOR IMPROVEMENT

This section describes barriers and challenges that children with special health care needs and their families face in accessing and utilizing existing services. Barriers and challenges are presented broadly, considering services that are generally available in the community for children with special health care needs and their families. If a barrier or challenge is specific to CSH, it is noted. After each barrier or challenge, suggestions for programs and initiatives that CSH could develop to reduce barriers and address challenges are presented.

In the assessment survey, respondents were asked to indicate whether certain issues ever make it more difficult for children with special health care needs to get the health care that they need. “[L]ack of evening and weekend services” and “long wait to schedule an appointment” were selected by the highest percentage of survey respondents (40.8% each), followed by “long wait at appointment time to see doctor” (29.9%) and “don’t know what types of services are available” (28.5%) (Figure 12). Respondents who selected “other” were asked to specify issues; a variety of issues were noted, and in particular long wait times on the phone and / or getting disconnected on the phone were mentioned. It should be noted that language barriers were only selected by a small percentage of respondents (1.8%), but this may be due to the fact that the assessment survey was administered only in English.

Figure 12: Top Ten Perceived Issues Parents’ Reported Making it Difficult for Children To Get Needed Health Care, 2016



DATA SOURCE: Children’s Specialized Hospital Community Health Needs Assessment Survey, 2016

NOTE: Responses fewer than 10% were not included in the figure

NOTE: “I have never experienced any difficulties getting care for my child(ren)” responses (17.3%) were not included in the figure

Location of Services, Transportation to Services, and Scheduling Barriers

Barriers and Challenges:

“They can’t get time off from work. They don’t get sick days or they don’t get time off.. Children’s Specialized doesn’t have evening appointments, and that’s a big thing.” – Key informant interviewee

“[I’m] not sure [what other services could be offered], [we] don’t really get a chance to do any. [I] don’t drive and can’t afford it.” – Survey respondent

“Children’s Specialized has great programs, like karate and swimming, in Mountainside. But they don’t offer that here. That’s a hard thing.” – Key informant interviewee

Interviewees noted that evening and weekend appointments are not consistently available. Similarly, 40.8% of assessment survey respondents indicated that a lack of evening and weekend appointments is a barrier to care. Interviewees noted that the weekday-only schedule for appointments may disproportionately impact families of limited means who may be working irregular schedules at jobs that do not offer sick time.

Transportation barriers were also raised by interviewees and survey respondents. As noted above, 20.4% of the assessment survey respondents indicated that providers are not available near them. While interviewees praised the expansion of CSH’s outpatient centers, some noted that additional locations would be beneficial to families. Interviewees stated that some families cannot drive far, or rely solely on public transportation and / or Medicaid-provided transportation which can be “a disaster.” It was stated that expanding services to additional locations would improve access for families who face transportation barriers. In addition to adding new locations, interviewees and survey respondents also suggested home visiting and telemedicine as ways to reach families with limited transportation.

At CSH specifically, a few interviewees and some survey respondents noted that certain services, like primary care, and recreational programs, like swimming and karate, are available in some CSH locations but not others. These assessment participants stated that they would like to see a more equitable distribution of services across the outpatient centers, as resources and space allows.

Suggestions for CSH:

“Without a doubt, a heavy expansion of outpatient centers is key. The big problem of access, that’s our key.” – Key informant interviewee

“We love the fact that we can have the option of virtual appointments. We think that’s one if the best tools out there. Especially if transportation isn’t available or if we’re not able to make an appointment, because of time frame.” – Survey respondent

Interviewees and survey respondents frequently noted that CSH should continue to expand the number of outpatient locations it has, particularly in southern New Jersey, as resources allow. Interviewees stated that this expansion would allow additional families, particularly those with limited transportation options, to access needed services. In addition to increasing the number of outpatient locations, interviewees and survey respondents suggested expanding medical services, such as screenings and Applied Behavior Analysis, and recreational offerings, such as Friday Night Fever and swimming, to additional sites that are already in operation but do not currently have a full range of services.

Interviewees did acknowledge that these types of expansions would be dependent upon resources, space, and available staff and volunteers.

Many survey respondents also stated that video appointments or video chats (e.g., telemedicine appointments) are useful, as are online parent support groups. A few interview respondents also echoed the parent survey respondents when raising technology-related suggestions. Interviewees noted that telemedicine (e.g., video appointments) are important for increasing access to services for those with limited transportation.

Language and Cultural Barriers and Challenges

Barriers and Challenges

“They don’t know where to go, they don’t have insurance or coverage, or their kids are translating for them. They also tend to be ignored at school because the parents are not involved. The school doesn’t flag issues, they just say ‘your child’s being bad’.” – Key informant interviewee

“There is a real need for practitioners who are bilingual in a variety of languages – this is a real issue in terms of the health care system.” – Key informant interviewee

A majority of key informant interviewees described barriers that exist for children with special health care needs and their families who do not speak English. While language barriers were not raised by many survey respondents, it should be noted that the survey was distributed in English only.

Interviewees noted that non-English-speaking parents may be more likely to work long hours at multiple jobs, and therefore it may be difficult for these parents to self-identify developmental and behavioral concerns in their children and also take time off of work for medical appointments, especially if they have other children and lack affordable child care. At the same time, due to time constraints and language barriers, these parents are less likely to be able to advocate for their children at school and at pediatricians’ offices, and thus developmental and behavioral health concerns may go undetected. Even when children are connected with care, interviewees described the particular challenges that non-English-speaking parents face when trying to coordinate care for their children across multiple providers, and between medical providers and the school systems.

In addition to describing language barriers, a few interviewees noted that children in certain communities, in particular Latino, Indian, Chinese, Korean, and Orthodox communities, may not be reached consistently. Interviewees expressed uncertainty about whether the care that is available is appropriate for families from these communities, and also stated that some communities are “closed off” and therefore that information about how to identify and treat children with special health care needs may be limited.

Suggestions for CSH:

“We don’t have bi-lingual pamphlets. So families think, ‘Am I even going to have someone there who can understand me?’” – Key informant interviewee

“That’s another way to reach these groups: through their religious spaces.” – Key informant interviewee

While CSH was described as being “progressive” in addressing language barriers, interviewees stated that more bilingual providers are needed, particularly for Spanish-speaking patients, in addition to interpreters and language lines, which a few interviewees described as “impersonal”. A few interviewees also noted that CSH may conduct targeted outreach to underserved populations, for example by developing pamphlets in multiple languages and by working with religious institutions.

Navigating and Coordinating Care

Barriers and Challenges:

“Families, especially underserved families who may face health literacy and language barriers, don’t have a good explanation of why they have to go from one place to other.” – Key informant interviewee

“Latino children, children of immigrants, Spanish-speaking children, they have a hard time navigating the system... it’s hard for families to navigate referrals and make connections between places, especially when a family needs to be communicating messages between schools and doctors.” – Key informant interviewee

“What ends up happening is families are doing their own care coordination, and that’s not what they should be doing. The system needs to do a better job. Strengthening the medical home and relationships between general pediatricians, nurse practitioners, surgical specialists, etc. And strengthening those community connections and resources.” – Key informant interviewee

A few interviewees described challenges that families, particularly those who do not speak English and/or have low levels of health literacy, face in navigating the health care system for children with special health care needs. Families may struggle to understand why they must see multiple providers, and may have trouble scheduling and tracking multiple appointments in different locations. Additionally, interviewees noted that while most children are insured through Medicaid, insurance does limit the providers families can see and the amount of services they can access. Interviewees described challenges families face in navigating care through their insurance and obtaining necessary referrals when needed. One interviewee and some survey respondents also noted that, at CSH specifically, it can be difficult for parents to find the information they need and even identify the right program or services to connect with through the CSH phone line.

A few interviewees also stated that parents or caregivers often become responsible for coordinating care between multiple providers, which can be burdensome and is not feasible for some families. Care coordination between CSH providers and other external providers, such as general pediatricians, was described as challenging by some interviewees. Particularly in developmental pediatrics, a diagnosis may be made at CSH but the actual services may be delivered in other settings such as schools and at home. As one interviewee stated, there is no “feedback loop” for communication between CSH providers and external providers that CSH patients have been referred to. However, only 8.1% of survey respondents indicated that “*lack of communication among child(ren)’s provider(s)/care team(s)*” was a barrier to care (Figure 12).

Within CSH, some interviewees stated that referrals between different departments, such as child psychology and development pediatrics, works well. However, other interviewees stated that there could be greater communication amongst CSH providers, particularly between therapists and

physiatrists, who may travel to multiple locations and therefore may not interact with therapists on a day-to-day basis.

Suggestions for CSH:

“Care coordination needs to happen at the community level. Larger group practices should have a care coordinator. It belongs in the practice, with the families, working closely with the providers, MDs, APNs.” – Key informant interviewee

“Look at other systems with multi-disciplinary specialties... there, you go to one clinic and see all the specialists all on the same day.” – Key informant interviewee

Interviewees frequently noted that, particularly for children with special health care needs, the burden of care coordination should fall to the health care system, not to families, as it too often does. Interviewees stated that care could be coordinated by a primary care physician, nurse practitioner, physician’s assistant, or care coordinator; this individual would help families arrange appointments, navigate insurance, and facilitate communication across providers. At facilities like CSH where many services are co-located, one interviewee noted that it would be ideal to coordinate and schedule all appointments that a family has on one day.

Interviewees mentioned different types of approaches to support care coordination in practice at CSH. As noted above, CSH was recognized by interview participants and survey respondents for the primary care they provide through their family-centered medical home. Interviewees noted that this medical home model, whether at CSH or at larger community pediatric practices, could be expanded and should include mental health professionals. One interviewee stated that under Medicaid Managed Care in New Jersey, there is a requirement for care coordination for children with special health care needs and children with disabilities, and noted that CSH may be able to *“offer care coordination models and services, particularly for more involved kids and high utilizers, as a product to managed care plans.”* Interviewees stressed that care coordination can lower costs, improve quality, and ease the burden that is currently on families.

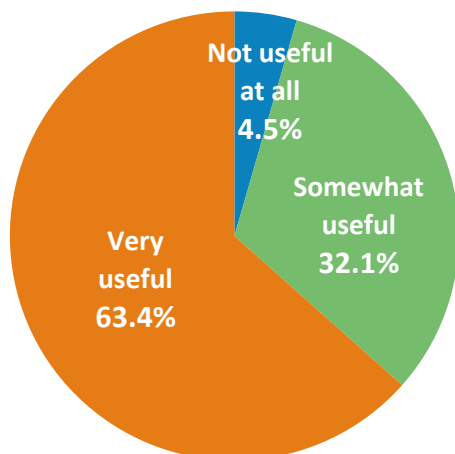
Use of Technology to Support Care Delivery

“We have so much on our plates – the more organized we [parents] can be, too, the more productive the visits are. We can tap into that [Patient] Portal. Give parents time to fill out questionnaires at home... like the intake form, questionnaires, demographics, medications, last hospitalizations.” – Key informant interviewee

“I’d love more access to the records - eg: the growth chart... when we were referred to an endocrinologist, I did not have that graph, only my own list of dates and measurements. Anything that makes it easier for us to access and share information with other providers -- perhaps even for the information from other providers to be shared with our CSH providers.” – Survey respondent

Technology may be leveraged to help children with special health care needs and their families navigate and coordinate care. Parent survey respondents were asked whether they had ever used the *My Children’s Specialized Patient & Family Portal*. About half of the survey respondents (48.9%) indicated that they had ever used this Portal. Among those respondents who indicated that they had used this Portal, a majority (63.4%) rated it as “very useful” and 32.1% rated it as “somewhat useful” (Figure 13).

Figure 13: Perceived Usefulness of the My Children’s Specialized Patient & Family Portal, 2016



DATA SOURCE: Children’s Specialized Hospital Community Health Needs Assessment Survey, 2016

When asked how technology can support the care of children with special health care needs and their families, survey respondents indicated that they would like to be able to use technology to contact providers directly, fill prescriptions, access medical records and progress reports or notes across multiple providers, track medications, schedule appointments online and easily view or print these appointments, and view bills and test results. One interviewee also noted that the Portal could be used to help parents prepare for appointments by allowing them to fill out forms related to things like medications and hospitalizations in advance at home.

Some survey respondents also suggested that educational or therapeutic games, apps, or videos could be offered for children with special health care needs, while a few others noted that apps for parents to track children’s behavior or medications would be useful. A few parents also noted that lists of resources and phone numbers could be posted online. Lastly, a few survey respondents stated that they preferred in-person contact rather than technology. As noted above, many survey respondents found video appointments (e.g., telemedicine) useful.

Community Awareness of Special Needs and Children’s Specialized Hospital

Barriers and Challenges:

“One thing that CSH is missing heavily is a connection with the community at large. Parents don’t know they need you until they need you. CSH needs to be more involved everywhere.” – Key informant interviewee

“On Spanish TV, I don’t see the commercials. We should be pushing PSAs on the African American radio stations, the BET network, Spanish networks.” – Key informant interviewee

While pediatricians and schools may refer children to CSH, parents can also recognize a need and seek out CSH directly. Some interviewees perceived a need for greater awareness of special health care needs, and also of Children’s Specialized Hospital and the hospital’s services, in the community at large. Survey respondents were not asked specifically about community awareness.

Suggestions for CSH:

“It has to be what’s for the best interest of the patient, what can we do for the patient. We need to focus on them and build partnership with communities and community centers.” – Key informant interviewee

A few interviewees suggested that CSH work to increase awareness of special needs and CSH’s services in the community at large. A few interviewees suggested that CSH organize events to *“invite the community into the hospital, and bring the hospital into the home”*. Interviewees also noted that targeted outreach to certain communities, such as the Latino community and the South Asian community, is important to reach populations that may be less likely to seek out services, especially if parents are undocumented. As part of this outreach, interviewees stressed that it is important to demonstrate that CSH offers culturally-competent care, including high-quality interpreter services and materials in multiple languages.

A few interview participants also noted that, to raise community awareness of CSH and also of how families can identify and address developmental and behavioral issues, CSH could build relationships with community organizations such as YMCAs, libraries, community centers, and churches and other religious spaces. These partnerships could involve sending educators to conduct screenings or workshops in community spaces, or could be collaborations around a one-time community event.

Community Physician Screening Practices and Awareness of Children’s Specialized Hospital

Barriers and Challenges:

“Primary care providers in clinics and in doctor’s offices, they see five patients scheduled in a half-hour, and so they’re not picking these issues up. I’m also not sure where community physicians are referring to. I’m not sure if they know about Children’s Specialized Hospital.” – Key informant interviewee

“Sometimes when a patient with ADHD walks in, there’s the moment of dread. [The pediatrician thinks], ‘I don’t have mental health support, I can’t get the psych screening because insurance won’t pay for it.’” – Key informant interviewee

“Unless you say ‘hey doctor, look at my kid!’ [it can be hard to raise developmental issues with a primary care physician]. That’s hard even for someone who speaks English.” – Key informant interviewee

Many interview participants noted that the community physician can play an important role in identifying children with special health care needs, particularly those who may be facing developmental delays and / or behavioral health issues. However, interviewees noted that pediatricians are often pressed for time and so cannot proactively identify developmental and behavioral health issues. While parents may be able to raise developmental concerns with their pediatricians, a few interviewees noted that language barriers can make it particularly difficult for some parents to advocate for the attention their child needs. Additionally, limited insurance reimbursement for screeners was noted. A few interviewees also stated that community physicians may not be aware of CSH and all the resources that are available. Survey respondents were not asked specifically about community physicians.

Suggestions for CSH:

“Start with doctors and providers – they’re the ground floor. Whether it’s at the hospital or the pediatrician, parents look to a medical provider to begin the process. We need to educate them. This is where change can happen.” – Key informant interviewee

“[We need to think] creatively about pumping out information to community pediatricians about common developmental problems with also some kind of link [via telephone or other ways] information) and publicizing Children’s availability.” – Key informant interviewee

“[Look into] whether there’s a possibility of having some kind of formalized relationship with some of larger pediatric practices, especially those that have social work or care coordination elements or who have become medical homes. CSH could explore this in collaboration with the patient-centered outcomes research and the American Academy of Pediatrics.” – Key informant interviewee

Interviewees frequently noted that community physicians are a primary gateway for children with special health care needs and their families to reach CSH and other specialized services. Some interviewees suggested that more marketing could be done directly to community physicians to ensure that they are aware of CSH’s services. Some interviewees also stated that more could be done to educate community physicians, beginning in medical school, around identifying and managing patients with developmental delays and behavioral health issues. However, as described above, interviewees also acknowledged that community physicians have limited time with patients. Therefore, in addition to education, interviewees suggested finding ways to support community physicians who work with children with special health care needs and stated that this support could be provided through informal mechanisms or formal partnerships. For example, interviewees noted that CSH could publicize their services directly to community physicians and reach out with an offer to “co-manage” patients, and also provide informal support like telephonic “office hours” for community physicians to reach CSH providers. A few interviewees noted that CSH could work through the American Academy of Pediatrics to reach and educate pediatricians on issues like managing patients with autism and ADHD. A few interviewees also suggested that CSH could explore building a formal relationship with large pediatric practices in the community that have become medical homes.

Coordination Between the Medical System and the Education System

Barriers and Challenges:

“The medical field thinks that they’re one entity, and education feels like they’re another. But when it comes to children who we’re educating, they [medical and education fields] are meshed together in ways that they [the two fields] don’t want to acknowledge. It’s drowning children.” – Key informant interviewee

“Working with schools, there are HIPPA and privacy laws, and also there is a cultural difference within the institutions. On both sides, people are taxed and over-worked. Oftentimes it’s difficult communicating between the two systems, even with a lot of effort.” – Key informant interviewee

Survey respondents frequently described challenges understanding and navigating the special education system at school, and particularly Individualized Education Plans (IEPs). A majority of interviewees also noted that there is a lack of coordination between the medical system and the education system.

Interviewees stated that limited time and funding within both systems can make communication difficult. Additionally, there is no formal structure or process for medical and educational providers to communicate; as a result, parents are left to coordinate and advocate for their children across systems. For example, one interviewee described situations where parents would ask therapists to call into IEP meetings at school and provide input over the phone. Coordinating between the medical and education systems can be especially challenging for families that do not speak English; one interviewee noted that IEP plans are not always made available in Spanish or the parents' primary language, which can result in confusion around the level of care being provided within the school.

A few interviewees noted that the school system and the medical providers sometimes disagree about a child's diagnosis, which can create an adversarial situation. For example, one interviewee described situations where medical providers have been told by school systems that they are "over-diagnosing kids with autism"; this diagnosis can result in higher costs for school systems.

Suggestions for CSH:

"[We need] resources for understanding how to connect the school to the doctors." – Survey respondent

"Having a relationship can help - remembering that we're all on the same side advocating for these kids. That's the kind of thing that technology can't help with. There is a human aspect to this." – Key informant interviewee

When survey respondents were asked about what types of support CSH could provide for parents, resources for working across both the medical and school system were requested frequently. For example, one survey respondent requested "*resources for understanding how to connect the school to the doctors.*" Interviewees stated that medical providers could support parents in accessing educational resources within schools – for example, a therapist could give a parent a specific list of what therapies are working well with the child, or a list of resources that the school might have, so that the parent can then request those services at school. Still, this type of support requires the parent to be the "middle-man." Interviewees noted that, ideally, therapists and providers could be involved in important meetings at schools, either in writing or on the phone.

Many key informant interviewees expressed a need for increased communication between medical providers and school systems, while also acknowledging that time and resources are limited within both the health care and the education system. Interviewees stated that, when medical providers and education staff do connect, it is often a good experience, but that there is no existing structure for this type of communication. Interviewees suggested that CSH providers and staff find ways to introduce themselves and build personal connections with local school systems, so that when the health care and education systems interact, in what can sometimes be conflicting ways, there is a base of goodwill and mutual respect. Interviewees also noted that technology, such as a secure web portal, could facilitate communication between medical providers and school staff. It should be noted that, because CSH serves children and families from a broad geographic area, it is not feasible for CSH to build direct connections with all the school systems that CSH patients attend.

PARTICIPANTS' VISION FOR THE FUTURE OF CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

"The one thing that I've noticed in working with so many parents is that no matter what brings you to looking for services, the services overlap. Whether it's for autism or traumatic brain injuries. Reading is reading, socializing is socializing. It doesn't matter what brings you there. We need a dialogue of parents across different diagnosis, causes and disabilities." – Key informant interviewee

"Make sure that any of the structural innovations in health care delivery include kids with disabilities and their families." – Key informant interviewee

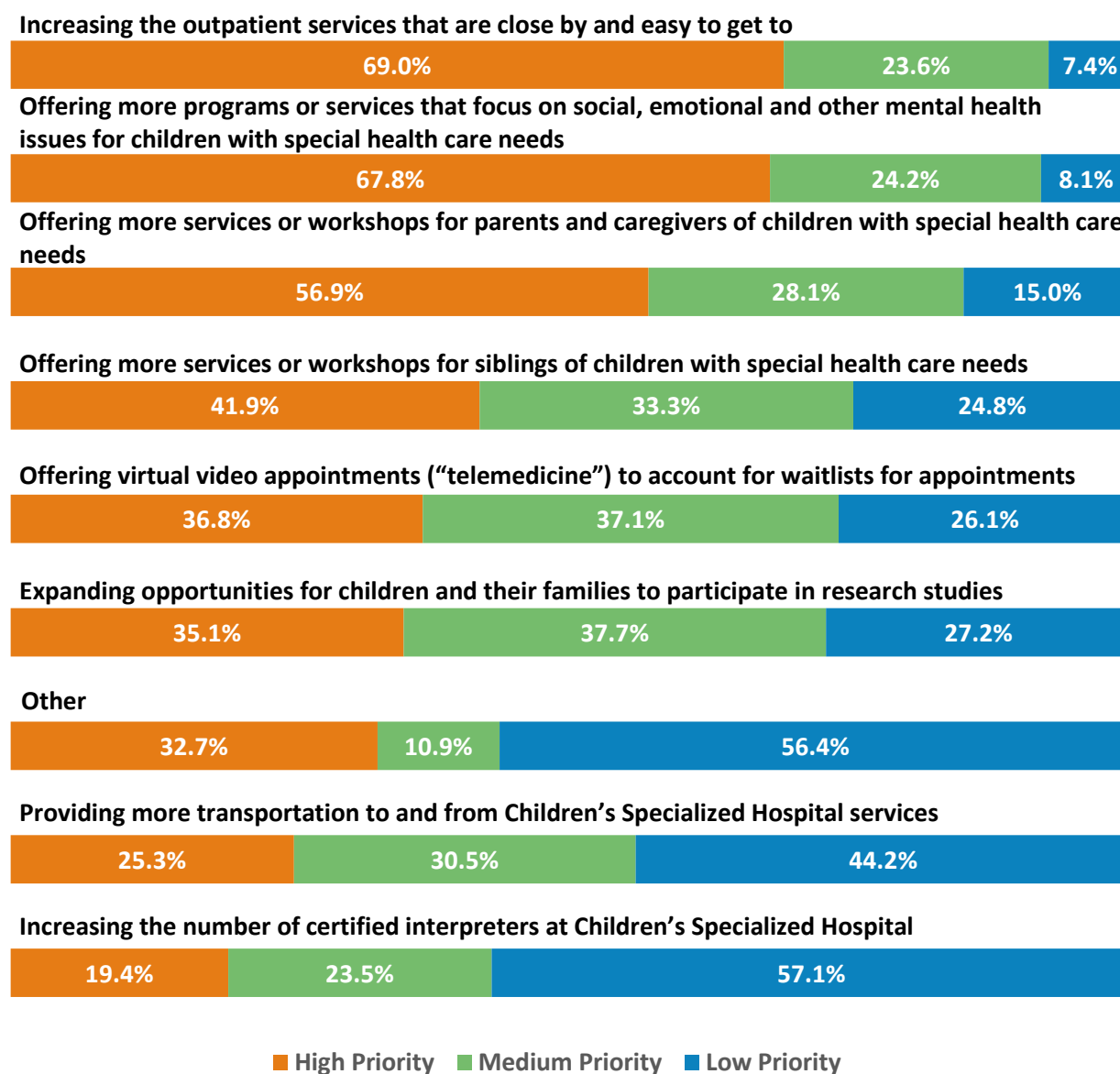
"In terms of a succession plan, it's about people in the hospital who can serve as leaders and create a presence in the community." – Key informant interviewee

When asked about a vision for the future, interview respondents shared various perspectives. One interviewee noted that support for children with special health care needs and their families is sometimes organized and separated by diagnosis. However, patients with the same diagnosis may have different needs, while patients with different diagnoses, such as autism or cerebral palsy, may have the same needs, such as occupational therapy. This interviewee hoped to see care for children with special health care needs organized by need, not diagnoses, and to see greater dialogue across families whose children have different diagnoses.

Another interviewee stressed that as structural innovations in the way health care is delivered are developed in the field at large, these innovations, such as care coordination, strengthening the medical home, and the development of accountable care organizations, must include children with special health care needs and children with disabilities. Lastly, a few interviewees noted the change in leadership at CSH, and the great amount of respect that both the outgoing and incoming President have gained. One interviewee suggested that, given this transitional period, it may be an ideal time to identify leaders at CSH who can serve as liaisons to maintain and strengthen CSH's presence in the community.

Survey respondents were asked to rate priorities for how future resources and funding should be allocated. Increasing outpatient services (69.0%) and offering more programs that focus on social, emotional and other mental health issues for children with special health care needs (67.8%) were rated as “high priority” by the majority of survey respondents (Figure 14). Providing more transportation was rated a high priority by only about a quarter (25.3%) of survey respondents, and increasing the number of certified interpreters was rated a high priority by only about a fifth (19.4%) of survey respondents (Figure 14); however, it should be noted that the survey was distributed in English only, and that the survey sample was highly educated, with 55% of respondents having obtained at least at college degree.

Figure 14: Parents’ Perceived Priorities For Future Resource Allocation and Spending, 2016



DATA SOURCE: Children’s Specialized Hospital Community Health Needs Assessment Survey, 2016

Conclusion

IMPACT OF ACTIONS TAKEN SINCE THE 2013 CHILDREN'S SPECIALIZED HOSPITAL ASSESSMENT

As described below, CSH has made progress on needs identified in their 2013 assessment. Additionally, the 2016 assessment has refined and expanded some of the 2013 identified needs:

- First, the 2013 assessment identified a need for greater visibility and education at the state level regarding the services and programs offered by CSH. Since 2013, CSH has made a concerted effort to increase its activities at the state level; to that end, senior leaders from CSH has provided testimony and engaged in advocacy activities at the state level. Expanding this 2013 need, the 2016 assessment also revealed a need for CSH to publicize its existing services and programs to some additional audiences: community physicians, current patients, and the community at large (particularly non-English speaking populations).
- A second need identified in the 2013 assessment was a need for increased communication between health plans and providers. In response, CSH has developed a payer strategic plan.
- A third need identified in the 2013 assessment was a need for the mental health network to be prevention-based and to participate in managed care. The 2016 assessment has refined this need to focus on a need for more pediatric mental health providers at CSH. Increasing the pediatric mental health providers on staff may decrease wait times for appointments and allow children to be seen in a timely manner, thus supporting a prevention-based approach.
- Lastly, in the 2013 assessment a need for the development of a succession plan was identified. In response, CSH has implemented a mentoring / coaching program for its Leadership team.

In addition to these four main needs, the 2013 assessment also identified other themes on which CSH has made progress. A list of these other themes and the associated activities undertaken by CSH may be found in Appendix D.

KEY THEMES FROM THE 2016 CHILDREN'S SPECIALIZED HOSPITAL ASSESSMENT

Through a review of the secondary data, a parent survey, and discussions with key leaders working at Children's Specialized Hospital and in the community, this assessment report provides an overview of perceptions of the health-related needs of children with special health care needs and their families, and identifies gaps, challenges, and opportunities for addressing these needs more effectively. Several overarching themes emerged from this synthesis related to barriers, challenges, and gaps:

- ***Children's Specialized Hospital is perceived as a caring, high-quality institution that is also a leader and an innovator.*** Many assessment participants described the excellent, compassionate care that CSH provides, and noted that CSH's staff, including administrators and direct health care providers, are personally invested in the patients and families that they serve. CSH was also recognized for leading innovative developments such as its family-centered medical home.
- ***Barriers, such as community physicians' limited time and awareness of Children's Specialized Hospital's Services, prevent the needs of some children from being identified.*** If a child is experiencing an issue that may require specialized care, parents may seek out a hospital like CSH directly, or pediatricians and schools may refer families. However, because community physicians have limited time to spend with patients and may not have the personnel, expertise, and reimbursement mechanisms to conduct screenings, needs may not be identified. Additionally, interviewees stated that certain communities, such as the Latino, Indian, Chinese, Korean, and Orthodox communities, may not be reached consistently and thus may not be aware of how to identify and treat children with special health care needs.
- ***Once special needs are identified in a child, issues such as long wait times, transportation and scheduling can prevent that child from getting the care that he or she needs.*** Once a family begins seeking specialized care for a child, they may face long wait times to schedule appointments, particularly for appointments with pediatric mental health providers. Additionally, transportation barriers, weekday-only appointment times, and location of services can limit the families' access to care.
- ***The current system of care is fragmented, leaving families to coordinate across multiple providers and between the health care and education systems, and creating particular challenges for non-English-speaking families.*** Interviewees frequently described care for children with special health care needs as fragmented or "scattered," leaving families to coordinate and communicate about complex care across multiple providers, and between a child's medical team and school. This type of coordination can be particularly challenging for non-English-speaking families.
- ***Opportunities exist to expand social and recreational programs for children with special health care needs, and educational and emotional support for their parents, caregivers, and siblings.*** Assessment participants frequently requested more social groups and physical activity opportunities for children with special health care needs. Many assessment participants also noted that parents, caregivers, and siblings of children with special health care needs may benefit from additional educational and emotional support, and from respite care. However, despite this need, it can be difficult for some parents and caregivers to carve out time to participate in additional workshops or support groups.

PRIORITIZED DESCRIPTION OF IDENTIFIED NEEDS AND POTENTIAL RESOURCES TO ADDRESS NEEDS

The following section summarizes the prioritized needs, including key barriers, challenges, and gaps to accessing health care and related services, and potential resources identified through this assessment to address these needs. The needs presented below were selected as priorities through review and discussion with key leaders at CSH. Prioritization was based on a variety of factors including the overall burden associated with the need (based on available secondary data and input from assessment participants), parents' priorities for future resource allocation (Figure 14), the impact of the need on vulnerable and underserved populations, the availability of feasible solutions to address the need, and the opportunity to build upon existing plans or initiatives to address the need.

As noted above, assessment participants perceived CSH to be a leader and provider of high-quality care. Thus, the potential resources presented below focus on how, as resources allow, CSH can capitalize on its established reputation among the community of children with special health care needs and their families in New Jersey to address needs by publicizing existing services, developing and expanding services, and pursuing partnerships.

Continue to publicize existing services and offerings to current patients and the community at large, reaching out particularly to non-English-speaking populations.

- **Description of Need:** While pediatricians and schools may refer children to CSH, parents can also recognize a need and seek out CSH directly. Assessment participants perceived a need for greater awareness of special health care needs, and also of CSH and the hospital's services, in the community at large.
- **Potential Resources and Opportunities:** CSH could increase its marketing to existing patients about services such as recreational offerings, which some survey respondents were not aware of, and the "Parent PAL" app, which some survey respondents noted will be very useful. Additionally, CSH may continue to publicize its services to increase awareness in the community at large. CSH may want to target its community outreach to underserved and/or non-English-speaking populations, promoting CSH's interpreter services and bilingual staff in particular in this outreach. Potential strategies for this type of marketing include developing additional brochures and other materials in Spanish, partnering with organizations that work directly with community members, and/or marketing directly to these communities (for example, through Spanish-speaking radio and television stations).

Build awareness among and provide support to community physicians.

- **Description of Need:** Assessment participants noted that community pediatricians may not have the time, expertise, and support to identify and manage patients with special health care needs.
- **Potential Opportunities and Resources:** To support community physicians in identifying and referring patients, CSH may reach out to practices to increase awareness of services. CSH could also offer advice and guidance on managing patients with diagnoses such as autism and ADHD, by for example holding "office hours" for community physicians.

Provide additional social and recreational services, in particular support groups and social skills groups, for children with special health care needs, their siblings, and their parents.

- **Description of Need:** A need for social and recreational services, including support and social skills groups for children with special health care needs and their families, emerged as a prominent theme in survey responses.
- **Potential Resources and Opportunities:** In response to the survey, CSH may consider expanding opportunities for children with special health care needs to socialize together and develop social skills; siblings may also be included in certain social events like outings to movies, concerts, or the beach. CSH may also increase opportunities for children with special health care needs to

participate in sports and / or physical activity programming, which could include team sports like soccer or other activities like yoga, gymnastics, and dance. CSH may want to expand support groups for parents, caregivers, and siblings, and may consider developing virtual or online communities. In addition to considering programs that provide emotional support, CSH may also expand educational workshops for parents, caregivers, and siblings that focus on issues like understanding diagnoses and coping with behavior at home.

Support parents in navigating the education system by promoting current workshops and providing additional resources.

- Description of Need: Challenges working with schools to develop Individualized Education Plans (IEPs) and ensure that children with special health care needs receive the support they need was frequently raised as a concern by assessment participants.
- Potential Opportunities and Resources: CSH may consider promoting existing parent workshops and providing additional resources that are focused on the topic of navigating the process for developing IEPs. While it is not feasible for CSH to connect directly with all the school systems that CSH patients attend, CSH staff may consider reaching out to superintendents and staff at local school systems in which a majority of CSH patients are enrolled, in order to build personal, informal connections that can facilitate communication processes.

Continue to expand access by offering evening and weekend appointments, increasing the outpatient center locations, and expanding telemedicine options.

- Description of Need: A need for expanded hours and locations, particularly for families of limited means, was raised frequently during the assessment. “Increasing outpatient services” was rated a “high priority” for future resource allocation by a majority of survey respondents.
- Potential Resources and Opportunities: CSH can consider offering evening and weekend appointments, opening additional outpatient center locations, and expanding existing recreational services that are currently located at only a few centers to additional centers. While additional locations may improve access for some families, others may still be limited by transportation or simply prefer to receive care at home. CSH can consider expanding its work around telemedicine.

Augment health care services for children with special health care needs including hiring more mental health providers and bilingual staff, and leveraging partnerships to offer dental and additional specialty care.

- Description of Need: A need for more pediatric mental health providers and more bilingual providers was an especially prominent theme in the assessment.
- Potential Resources and Opportunities: If feasible given the supply of providers, CSH could hire additional staff in these areas. The hospital could also explore whether it can leverage its existing partnerships, for example with the Robert Wood Johnson Medical School, to offer dental and additional specialty care (e.g., gastroenterology) for children with special needs.

Explore opportunities to promote care coordination.

- Description of Need: Assessment participants described a need for greater care coordination so that parents do not have to coordinate and communicate across multiple providers and systems. This need was described as particularly important for non-English-speaking families.
- Potential Resources and Opportunities: CSH may explore models for supporting families around care coordination, such as employing patient navigators and care coordinators and/or expanding its family-centered medical home, which was praised by participants and key stakeholders who recognized CSH’s innovation in this area. CSH may also be able to leverage its patient portal in helping families navigate and coordinate care.

APPENDIX A: ORGANIZATIONS AND SECTORS ENGAGED IN KEY INFORMANT INTERVIEWS

Key informant interviews were conducted in January, February, and April 2016. The following organizations and sectors were engaged:

| Organization | Sector |
|--|----------------------------|
| Children’s Specialized Hospital, Family Faculty | INTERNAL / PARENT |
| Children’s Specialized Hospital, Family Advisory Council | INTERNAL / PARENT |
| Children’s Specialized Hospital, Developmental & Behavioral Pediatrics | INTERNAL |
| Children’s Specialized Hospital, The Autism Program | INTERNAL |
| Children’s Specialized Hospital, Board of Trustees | INTERNAL |
| Children’s Specialized Hospital Foundation, Board of Trustees | INTERNAL |
| Horizon NJ Health | PAYER |
| KDH Enterprises, LLC | EDUCATION |
| New Jersey Department of Health | PUBLIC HEALTH / GOVERNMENT |
| Robert Wood Johnson Medical School, The Boggs Center on Developmental Disabilities | RESEARCHER |
| Robert Wood Johnson University Hospital, Department of Pediatrics | COMMUNITY PHYSICIAN |

APPENDIX B: 2016 CHILDREN’S SPECIALIZED HOSPITAL COMMUNITY HEALTH NEEDS ASSESSMENT: QUANTITATIVE PARENT SURVEY RESULTS

TABLE 1. ACCESS TO SERVICES

| In general, how easy or hard is it for your child(ren) with special health care needs to access the following services? | |
|---|-------|
| <i>Primary care for children with special health care needs (N=238)</i> | |
| Very easy | 26.9% |
| Easy | 30.3% |
| Not easy or hard | 22.7% |
| Hard | 14.7% |
| Very hard | 5.5% |
| <i>Specialty care for children with special health care needs (N=272)</i> | |
| Very easy | 24.3% |
| Easy | 23.2% |
| Not easy or hard | 21.0% |
| Hard | 19.9% |
| Very hard | 11.8% |
| <i>Dental care for children with special health care needs (N=188)</i> | |
| Very easy | 12.2% |
| Easy | 26.1% |
| Not easy or hard | 26.1% |
| Hard | 19.7% |
| Very hard | 16.0% |
| <i>Behavioral/mental health care for children with special health care needs (N=238)</i> | |
| Very easy | 16.8% |
| Easy | 22.3% |
| Not easy or hard | 19.7% |
| Hard | 18.1% |
| Very hard | 23.1% |
| <i>Recreational programs and services for children with special health care needs (e.g., camps, concerts, social events, art programs, sports programs, etc.) (N=220)</i> | |
| Very easy | 11.4% |
| Easy | 19.5% |
| Not easy or hard | 20.5% |
| Hard | 25.0% |
| Very hard | 23.6% |
| <i>Educational programs and services for children with special health care needs (e.g. preschool, special education programs, K – 12 education, etc.) (N=222)</i> | |
| Very easy | 12.6% |
| Easy | 24.3% |
| Not easy or hard | 19.4% |
| Hard | 27.0% |
| Very hard | 16.7% |

TABLE 2. USEFULNESS OF SPECIALTY PROGRAMS

| Please indicate how useful or not useful you have found each of the following specialty programs | |
|---|-------|
| <i>Camps and Clubs (Camp Chatterbox, BECOME Program, Pal's Paradise, Camp Kresge) (N=72)</i> | |
| Very useful | 41.7% |
| Somewhat useful | 30.6% |
| Not useful at all | 27.8% |
| <i>Community Recreation Programs (Martial Arts Program, Adaptive Aquatics Program, Friday Night Fever) (N=99)</i> | |
| Very useful | 56.6% |
| Somewhat useful | 23.2% |
| Not useful at all | 20.2% |
| <i>Lightning Wheels (Paralympic Sports Club) (N=66)</i> | |
| Very useful | 53.0% |
| Somewhat useful | 22.7% |
| Not useful at all | 24.2% |
| <i>Peer Mentor Program (N=68)</i> | |
| Very useful | 58.8% |
| Somewhat useful | 20.6% |
| Not useful at all | 20.6% |
| <i>Early Developmental Screenings (N=177)</i> | |
| Very useful | 76.8% |
| Somewhat useful | 18.6% |
| Not useful at all | 4.5% |

TABLE 3. BARRIERS TO CARE

| Have any of these issues ever made it more difficult for your child(ren) to get the health care that s/he needed? (N=284) | |
|--|-------|
| Lack of transportation | 12.3% |
| Have no regular source of healthcare | 2.1% |
| Cost of care/co-pays | 20.1% |
| Lack of evening and weekend services | 40.8% |
| Insurance problems/ lack of coverage | 23.2% |
| Child(ren) was not eligible for services | 17.3% |
| Language problems/ could not communicate with provider or office staff | 1.8% |
| Discrimination/ unfriendliness of provider or office staff | 5.6% |
| Don't know what type of services are available | 28.5% |
| No available provider near me | 20.4% |
| Lack of communication among child(ren)'s provider(s)/care team(s) | 8.1% |
| Long wait at appointment time to see doctor | 29.9% |
| Long wait to schedule an appointment | 40.8% |
| I have never experienced any difficulties getting care for my child(ren) | 17.3% |
| Other | 10.9% |

TABLE 4. PRIORITIES FOR THE FUTURE

| When deciding how future resources should be spent, what priority do you think should be given to the following? | |
|---|-------|
| <i>Increasing the outpatient services that are close by and easy to get to (N=271)</i> | |
| Low Priority | 7.4% |
| Medium Priority | 23.6% |
| High Priority | 69.0% |
| <i>Providing more transportation to and from Children's Specialized Hospital services (N=269)</i> | |

| | |
|---|-------|
| Low Priority | 44.2% |
| Medium Priority | 30.5% |
| High Priority | 25.3% |
| <i>Offering virtual video appointments (“telemedicine”) so that if there is a waitlist for an in-person appointment your child(ren) can be seen sooner through a video appointment that takes place at home (i.e., you do not travel to see a provider) (N=272)</i> | |
| Low Priority | 26.1% |
| Medium Priority | 37.1% |
| High Priority | 36.8% |
| <i>Increasing the number of certified interpreters at Children’s Specialized Hospital (N=268)</i> | |
| Low Priority | 57.1% |
| Medium Priority | 23.5% |
| High Priority | 19.4% |
| <i>Expanding opportunities for children and their families to participate in research studies (N=268)</i> | |
| Low Priority | 27.2% |
| Medium Priority | 37.7% |
| High Priority | 35.1% |
| <i>Offering more programs or services that focus on social, emotional and other mental health issues for children with special health care needs (N=273)</i> | |
| Low Priority | 8.1% |
| Medium Priority | 24.2% |
| High Priority | 67.8% |
| <i>Offering more services or workshops for parents and caregivers of children with special health care needs (e.g., support groups, classes, etc.) (N=274)</i> | |
| Low Priority | 15.0% |
| Medium Priority | 28.1% |
| High Priority | 56.9% |
| <i>Offering more services or workshops for siblings of children with special health care needs (e.g., support groups, classes, etc.) (N=270)</i> | |
| Low Priority | 24.8% |
| Medium Priority | 33.3% |
| High Priority | 41.9% |
| <i>Other (N=55)</i> | |
| Low Priority | 56.4% |
| Medium Priority | 10.9% |
| High Priority | 32.7% |

TABLE 5. USE AND USEFULNESS OF MY CHILDREN’S SPECIALIZED PATIENT AND FAMILY PORTAL

| | |
|--|-------|
| Have you ever used the My Children’s Specialized Patient & Family Portal? (N=274) | |
| Yes | 48.9% |
| No | 51.1% |
| In your opinion, how useful is the My Children’s Specialized Patient & Family Portal? (N=134) | |
| Very useful | 63.4% |
| Somewhat useful | 32.1% |
| Not useful at all | 4.5% |

TABLE 6. FREQUENCY OF VISITING CHILDREN’S SPECIALIZED HOSPITAL

| | |
|--|-------|
| In the last 12 months, how many times have you visited Children’s Specialized Hospital to get care for your child(ren)? (N=261) | |
| 0 times | 6.5% |
| 1 to 5 times | 54.0% |
| 6 to 9 times | 10.0% |

| | |
|------------------|-------|
| 10 or more times | 29.5% |
|------------------|-------|

TABLE 7. HEALTH INSURANCE COVERAGE

| At this time, is your child(ren) covered by health insurance?* (N=262) | |
|---|-------|
| Yes, private health insurance (through employer/spouse’s employer or bought on own) | 57.3% |
| Yes, government plan (Medicaid/State Children’s Health Insurance Program or other) | 37.0% |
| Yes, both private health insurance and government plan | 5.7% |

DATA SOURCE: Children’s Specialized Hospital Community Health Needs Assessment Survey, 2016

NOTE: For all questions with "Don't Know" or "Not Applicable" response options, respondents who selected those options were excluded from frequency calculations (Questions 2, 3, and 9).

* One respondent indicated their child is not currently covered by health insurance. That respondent was excluded from frequency calculations.

APPENDIX C: 2016 CHILDREN’S SPECIALIZED HOSPITAL COMMUNITY HEALTH NEEDS ASSESSMENT: QUALITATIVE PARENT SURVEY RESPONSES

A complete list of both parent and non-parent responses to the open-ended survey questions may be found in Appendix C, which is included as a separate Excel document.

Appendix D. Impact of Actions Taken to Address Needs and Themes Identified in 2013 CSH Assessment

As described below, CSH has made progress on the needs identified in their 2013 assessment. Additionally, this 2016 assessment has refined and expanded some of the 2013 identified needs:

- First, the 2013 assessment identified a need for greater visibility and education at the state level regarding the services and programs offered by CSH. Since 2013, CSH has made a concerted effort to increase its activities at the state level; to that end, senior leaders from CSH has provided testimony and engaged in advocacy activities at the state level. Expanding this 2013 need, the 2016 assessment also revealed a need for CSH to publicize its existing services and programs to some additional audiences: community physicians, current patients, and the community at large (particularly non-English speaking populations).
- A second need identified in the 2013 assessment was a need for increased communication between health plans and providers. In response, CSH has developed a payer strategic plan.
- A third need identified in the 2013 assessment was a need for the mental health networks to be prevention-based and to participate in managed care. This 2016 assessment has refined this need to focus on a need for more pediatric mental health providers at CSH. Increasing the pediatric mental health providers on staff may decrease wait times for appointments and allow children to be seen in a timely manner, thus supporting a prevention-based approach.
- Lastly, in the 2013 assessment a need for the development of a succession plan was identified. In response, CSH has implemented a mentoring / coaching program for its Leadership team.

In addition to these four main needs, the 2013 assessment also identified other themes on which CSH has made progress, as follows:

| 2013 Theme | Progress Made |
|--|---|
| 1. Fundraising must increase to meet expanding need | <ul style="list-style-type: none"> • Initiated new Children’s Miracle Network Hospitals (CMNH) pilot projects: Miracle Marathon and Dance Dash, added new Dance Marathons, launched electronic wish list to enhance online giving • Launched new fundraising campaign in support of strategic priorities |
| 2. Strong physician leadership is needed to match overall leadership | <ul style="list-style-type: none"> • New practitioners hired (17 physicians, 12 APNs) • Implemented medical leadership structure |
| 3. Integration process within campus needs maturity, specifically in research | <ul style="list-style-type: none"> • Developed collaborative programs with Robert Wood Johnson University Hospital, or RWJUH, (various stages of implementation) for Pain, Diabetes, Neonatal Abstinence Syndrome (NAS), Infant High Risk follow up, Asthma • Launched program with RWJUH in Bariatric Surgery and Concussion • Fully implemented CSH Research Center Distinguished Lecture Series bringing world famous scientists to the academic pediatric campus |
| 4. Opportunity to build brand recognition through internal / external communications | <ul style="list-style-type: none"> • Underwent a process, in 2014, to develop comprehensive brand positioning and messaging, which was validated throughout the year by internal and external research • Process was translated into an integrated external brand awareness campaign including television, radio, print, digital, outdoor, and SEM advertising |

| | |
|--|--|
| | <ul style="list-style-type: none"> • Brand awareness campaign ran throughout 2015 and is planned to continue running in 2016 and beyond |
| 5. Opportunity to build research and programs | <ul style="list-style-type: none"> • Formalized relationship with Kessler Foundation to include postdoctoral research fellows in mobility and cognition, and scientists working on pediatric rehab projects • Awarded multiple grants totaling over \$3 million (e.g., approval for continuation of The Governor’s Council for Medical Research and Treatment of Autism grant; awarded the NJ Commission on Brain Injury Research grant; awarded additional grants involving pediatric traumatic brain injury; awarded a grant for Patient Centered Medical Home for children with autism spectrum disorder) |
| 6. External audiences need to understand value proposition | <ul style="list-style-type: none"> • Achieved national rehabilitation recognition for individual nurse leader • Presented to national and international presentation audiences • In 2014, named one of nine of the country’s Top Children’s Hospitals by the LeapFrog Group for quality and safety |