

# COMMUNITY HEALTH NEEDS ASSESSMENT

# CHILDREN'S SPECIALIZED HOSPITAL

2019

#### **ACKNOWLEDGMENTS**

The following partners led the Children's Specialized Hospital (CSH) Community Health Assessment:

#### CHILDREN'S SPECIALIZED HOSPITAL EXECUTIVES AND SENIOR TEAM

- Warren E. Moore, FACHE
   President & CEO, Children's Specialized Hospital
   Senior Vice President, Pediatric Services, RWJBarnabas Health
- Bonnie Altieri, PhD., RN, NEA-BC
   Senior Vice President & Chief Nursing Officer, CSH
- Ruth K. Bash, MPA, FACHE
   Vice President & Chief Culture Officer, CSH
- Charles Chianese, MBA
   Vice President & Chief Operating Officer, CSH
- Joseph J. Dobosh, Jr., MBA
   Vice President & Chief Financial Officer, CSH
- Michael R. Dribbon, PhD.
   Vice President of Business Development & Chief Innovation & Research Officer, CSH
- Matthew B. McDonald III, MD
   Vice President & Chief Medical Officer, CSH

#### CHILDREN'S SPECIALIZED HOSPITAL OVERSIGHT COMMITTEE

- Warren E. Moore, FACHE
   President & CEO, Children's Specialized Hospital
   Senior Vice President, Pediatric Services, RWJBarnabas Health
- Bonnie Altieri, PhD., RN, NEA-BC
   Senior Vice President & Chief Nursing Officer, CSH
- Ruth K. Bash, MPA, FACHE
   Vice President & Chief Culture Officer, CSH
- Charles Chianese, MBA
   Vice President & Chief Operating Officer, CSH
- Joseph J. Dobosh, Jr., MBA
   Vice President & Chief Financial Officer, CSH
- Michael R. Dribbon, PhD.
- Vice President of Business Development & Chief Innovation & Research Officer, CSH

   Matthew B. McDonald III, MD
- Vice President & Chief Medical Officer, CSH
- Megan Muller, Senior Communications Specialist, CSH
- Donna Provenzano, Director of Patient and Family Centered Care, CSH
- Linda Waddell, Family Faculty, CSH
- Katie Drummond, Volunteer and CSH Family Advisory Council Member

#### RWJ BARNABAS HEALTH COMMUNITY HEALTH NEEDS ASSESSMENT STEERING COMMITTEE

The RWJ Barnabas Health CHNA Steering Committee oversees the 2018-2019 CNA process to update Hospitals CNAs and create new Implementation/Community Health Improvement Plans. The key tasks of the Steering Committee include:

- Oversight and guidance of CHNA implementation plan development
- Review facility implementation/health improvement plans and results
- Review of suggested priorities for facility implementation planning
- Share strategies and best practices

#### Members of the RWJ Barnabas Health CHNA Steering Committee include:

- Jen Velez, Executive Vice President, Community and Behavioral Health, Committee Chair
- Michellene Davis, Executive Vice President, Corporate Affairs
- Bryan Soltes, System Vice President, Network Development, Oncology Services
- Connie Greene, Vice President, Health Institute for Prevention and Recovery
- Joseph Jaeger, DrPH, Chief Academic Officer
- Barbara Mintz, Senior Vice President, Health and Wellness
- Jessica Israel, M.D., Corporate Chair, Geriatrics
- Michael Knecht, Corporate Vice President, Strategic Messaging and Marketing
- Ernani Sadural, M.D., Director of Global Health for Barnabas Health
- Richard Henwood, Vice President, Finance
- Tamara Cunningham, Vice President, System Development/Planning
- Hospital Representatives:
  - Céu Cirne Neves, Vice President, Physician and Support Services, Saint Barnabas Medical Center (Designee: Margie Heller, Vice President, Community Health & Global Strategic Partnerships, Saint Barnabas Medical Center)
  - Darrell K. Terry, Sr., MHA, MPH, FACHE, President and CEO, Newark Beth Israel Medical Center (Designee: Kim Cook, Director, Community Relations & Volunteer Services)
  - o Frank Mazzarella, M.D., Chief Medical Officer, Clara Maass Medical Center (Designee: Fran Monteleone, Director, Physician Relations and Community Outreach)
  - Judy Colorado, Chief Nursing Officer and Vice President of Patient Care Services, Monmouth Medical Center Southern Campus (Designee: Jean McKinney, Community Education Department)
  - Anna Burian, Vice President of Ambulatory Care Services, Monmouth Medical Center (Designee: Jean McKinney, Community Education Department)
  - o Teri Kubiel, DNP, Vice President, Patient Experience and Community Affairs
  - Shari Beirne, Director of Marketing and Patient Satisfaction, Barnabas Health Behavioral Health Center
  - Serena Collado, Director, Community Health, Robert Wood Johnson University Hospital Somerset
  - Mariam Merced, Director, Community Health Promotions, Robert Wood Johnson University Hospital New Brunswick
  - Donna Mancuso, Manager, Public & Community Affairs, Robert Wood Johnson University Hospital Rahway
  - o Ruth Bash, Vice President & Chief Culture Officer, Children's Specialized Hospital
  - o Irene Borgen, Vice President, Quality and Standards, Jersey City Medical Center

 Diane Grillo, Vice President, Health Promotion, Robert Wood Johnson University Hospital Hamilton (Designee: Lauren Stabinsky, Director Community & Corporate Health, Robert Wood Johnson University Hospital Hamilton)

#### CHILDREN'S SPECIALIZED HOSPITAL STEERING COMMITTEE CONSULTANT ADVISORS

**Steering Committee Technical Advisors:** 

- Withum, Smith & Brown (Scott Mariani)
- New Solutions Inc. (Nancy Erickson<sup>1</sup>)
- Bruno & Ridgway, Inc. (Joseph Ridgway)

Questions regarding the Community Needs Assessments should be directed to RWJ Barnabas Health System Development & Planning at <a href="mailto:BHPlanningDept@RWJUH.org">BHPlanningDept@RWJUH.org</a>.

<sup>1</sup> The CHA's development consultants, New Solutions, Inc., have planned and conducted numerous community needs assessments and implementation plans with multiple organizations including individual hospitals, health systems, other health care and community organizations such as consortia comprised of a wide range of participant organizations. The NSI team, of which two are Ph.D. prepared, includes: planning consultants, market researchers, epidemiologists, computer programmers and data analysts. NSI has extensive regional and local community knowledge of health issues, community services and provider resources for the community reviewed by this assessment. This expertise, as well as the methodological and technical skills of the entire staff, was brought to bear in conducting this Community Health Needs Assessment.

#### **TABLE OF CONTENTS**

Exe	ecuti	ive Summary	ES-1					
1.	Int	roduction	1					
2.	Methodology							
	A.	Prioritization Process	2					
	В.	Primary Data Sources	3					
	C.	Secondary Data Sources						
	D.	Health Profile						
	E.	Assets and Gaps	3					
	F.	Resource Inventory	4					
3.	Coi	Community Health Needs Assessment Survey Data – Summary Tables5						
	A.	Ease/Difficulty of Accessing Community Services for						
		Children with Special Health Care Needs						
	В.	Barriers to Accessing Health Care for Children with Special Health Care Needs	9					
	C.	Usefulness of Specialty Programs and Services for						
		Children with Special Health Care Needs						
	D.	Priority of Solutions/Resources Serving Children with Special Health Care Needs						
	Ε.	Strengths and Opportunities of Community Services Offered						
	F.	Familiarity and Usage of Facilities that Service Children with Special Health Care Needs						
	G.	Sources from Which to Obtain Health Care Information	22					
	Н.	Demographics	23					
	I.	Sampling of Additional Verbatim Comments	25					
4.		w Jersey State and CSH Counties Health Profile						
	A.	Demographics						
	В.	Poverty Status and Education						
	C.	Population of Children with Special Health Care Needs						
	D.	Birth Defects Registry						
	E.	Low Birth Weight Infants in New Jersey	42					
5.	Assets and Gaps Analysis							
		Economic Status						
	В.	Birth Defects						
	C.	Health and Health Care	44					
Ар	-	dices						
		CSH Implementation Plan Results						
		Secondary Data Sources						
	C.	Resource Inventory	54					

#### **EXECUTIVE SUMMARY**

#### **BACKGROUND**

Children's Specialized Hospital (CSH) is a leader in offering high quality health care and services for children with special health care needs. CSH provides support to children with special needs from birth to 21 years of age to help them live and thrive in the community. CSH is an affiliate of the RWJ Barnabas Health System. The Community Health Needs Assessment (CHNA) is designed to ensure the hospital continues to effectively and efficiently serve children with special needs. The CHNA was developed in accordance with federal rules and statues (the Affordable Care Act) which added section 501(r) to the Internal Revenue Code. The aim of CHNA is to identify primary health care needs for the community and to suggest potential solutions to identified health needs. This assessment builds upon the 2016 CHNA report for the CSH. The 2016 implementation plan results are reviewed in Appendix A.

# Sussex,NJ Passaic,NJ Morris,NJ Essex,NJ Hunterdon,NJ Middlesex,N, Mornouth,NJ Ocean,NJ Burlington,NJ Gloucester,NJ Salem,NJ Atlantic,NJ Camberland,NJ Camberla

**CSH Service Area** 

CSH has 13 different locations in nine (9) counties including Atlantic, Essex, Hudson, Mercer, Middlesex, Ocean, Passaic, Somerset and Union in New Jersey. The facilities provide inpatient and outpatient services as well as long term care and specialty care. This report includes quantitative data; primary data collected through surveys of parents and caregivers of children with special healthcare needs, and secondary data including public health and demographic data at national, State, and County level.

#### Summary of the Report

The primary objective of this CHNA report is to determine the difficulty in accessing community services and barriers to accessing health care for children with special health care needs. This report includes results from both primary and secondary data sources. Based on secondary data sources, the State of New Jersey has higher percentage of children with special health care needs and a higher percentage of students (6-21 years) received special education services as compared to the U. S. overall.

Survey findings indicate that parents and caregivers find it more difficult to access certain services (behavioral health, transitional services and support groups) than others. North Jersey residents find it more difficult to access dental services compared to South Jersey residents.

Other significant barriers determined by this CHNA include:

- Insurance issues
- Access to Care (long wait times, difficulties in scheduling appointments, cost concerns, hours of operation)
- Not knowing the types of services available

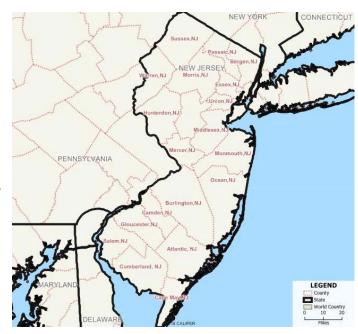
The survey also determined that specialty programs (transition to adult services and community recreational program) are seen as very useful to parent/ caregivers. In addition, early developmental screenings, camps/clubs, peer mentors, online portals, Paralympic sports are all viewed as very useful.

#### Service Area

Children's Specialized Hospital has 13 locations serving residents throughout the State as well as residents from other states such as New York and Pennsylvania.

New Jersey is the fourth smallest and eleventh most-populous state in the United States and is located in the Northeastern part of the nation. The State of New Jersey is one of the most diversely populated states by race and ethnicity. Almost half of children under 18 have at least one parent who is non-Hispanic White.

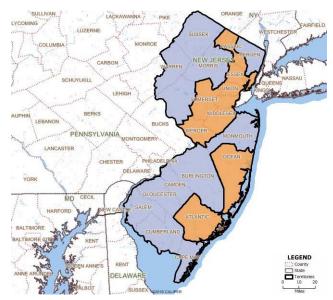
New Jersey is made up of 21 counties. Among the 21 counties, Bergen, Essex and Union counties are part of the New York city Metropolitan area. Essex, Hudson, Passaic and Union counties are considered as North



Jersey counties. The majority (~40%) of the State's population resides near New York City, Philadelphia and eastern Jersey Shore. The most southern and northwestern counties of State are less densely populated as compared to the eastern portion of the State. Bergen is one of the wealthiest and most populous Counties in the State. Middlesex and Essex Counties are the State's second and third most populous Counties, respectively. Hudson County is geographically the smallest, the most densely populated and the fastest growing County in State. Burlington County is the second largest county in geographical size in the state. Atlantic County, home to the resorts of Atlantic City, is second largest County by geographic size and located in the southern portion of the state east of Philadelphia. Ocean is among the fastest growing Counties in the State and is located along the Jersey Shore.

#### 1. INTRODUCTION

The Children's Specialized Hospital Community Health Needs Assessment is designed to ensure that the hospital continues to effectively and efficiently serve the needs of children with special health needs in New Jersey. The CHNA was developed in accordance with all federal rules and statues, specifically, PL 111-148 (The Affordable Care Act) which added section 501(r) to Internal Revenue Code. The CSH needs assessment was undertaken in this context and developed for the purpose of enhancing health and quality of life throughout the State. This assessment builds upon the CHNA completed in 2016. The 2016 Implementation Plan results are reviewed in **Appendix A**.



**Highlighted Counties Show CSH Locations** 

CSH is a member of RWJ Barnabas Health, which convenes a multi-disciplinary, multi-facility Steering Committee that provides additional support and leadership. Also, insight and expertise from Children Specialized Hospital CHNA Oversight Committee helps to identify health assets, gaps, disparities, trends, and priorities. The methodology section details the data collection process and analysis. The CSH needs assessment was developed for the purpose of enhancing the health and quality of life throughout New Jersey. To this end, both internal and external data were used to understand recent health indicators and opportunities to provide a positive impact on children with special health care needs.

Children's Specialized Hospital (CSH) is a national leader providing health care services for children with special health care needs. CSH, an affiliate of RWJ Barnabas Health System, is one of the best and largest pediatric rehabilitation and specialty care hospitals. CSH facilities are located in nine (9) counties at 13 different sites. The nine (9) Counties include Atlantic, Essex, Hudson, Middlesex, Ocean, Union, Mercer, Somerset and Passaic Counties.

The vision of Children's Specialized Hospital is a world where all children can reach their full potential. The mission of CSH is to be the preeminent provider of specialized healthcare to infants, children and young adults. The hospital provides inpatient and outpatient care services for children facing special health challenges ranging from chronic illnesses to developmental and behavioral issues. Example of such challenges include autism, Attention Deficient Hyperactivity Disorder (ADHD), brain injury, mobility, birth defects and cognition. CSH also provides several specialty programs such as early developmental screenings, community recreation programs (e.g., Sports Connection and Social Connection). These programs help to develop social skills, improve confidence, promote health and education and motivate children to live independently.

Among these 13 CSH facilities, 10 have outpatient services only and remaining three (3) facilities have inpatient, outpatient, and long-term care services for children with special health care needs.

#### 2. METHODOLOGY

CSH developed an evidence-based process to determine the health needs of New Jersey residents. CHNA data sources include both primary and secondary data to identify public health needs in the community. Most of the public health secondary data used was at the national and State or County level.

The flow chart below identifies the CHNA and implementation process employed.



#### A. PRIORITIZATION PROCESS

Following the local oversight committee's review of primary and secondary source data on August 19, 2019, a list of 8 issues was identified by consultants as common themes of the research. These included:

- Dental services
- Access to recreational programs
- Awareness of services
- Transitional services
- Behavioral/ Mental Health services
- Support Group
- Peer Mentor services
- Enhanced access for working parents

A ballot was developed, and a survey sent to members of the Oversight Committee asking them to rank each issue based upon the following criteria:

- Number of people impacted
- Risk of mortality and morbidity associated with the problem
- Impact upon vulnerable population
- Meaningful progress can be made within a three-year period.
- Community's capability/competency to impact

A tally of ballots resulted in the following three issues being selected:

- 1. Behavioral/Mental Health Services
- 2. Transitional Services
- 3. Enhanced Access

#### B. PRIMARY DATA SOURCES

To obtain input from the community, CSH conducted a **Community Health Needs Survey**. This on-line survey was conducted among parents, caregivers and those who have a relationship with children with special health care needs (i.e., developmental disorders, autism, cerebral palsy, ADHD, head injuries, etc.). The hospital deployed multiple channels to encourage broad participation including posting the survey link on the hospital web pages and on social media sites, sharing the link with stakeholder organizations and speaking about it in community meetings. The survey resulted in 263 participants during the study period of December 1, 2018, to April 30, 2019. The survey averaged 15-20 minutes in length. This CHNA incorporates results of the survey.

A survey of the CHNA Oversight Committee members provided additional insights and perspectives.

#### C. SECONDARY DATA SOURCES

The secondary data sources included U.S. Census Bureau, Center for Disease control and Prevention, U.S. Department of Education, New Jersey Department of Health, New Jersey Birth Defects Registry, Special Child Health and Early Intervention Services, National Survey of Children with Special Health Care Needs Chartbook, among others. (See **Appendix B** for a complete list.)

#### D. HEALTH PROFILE

This section provides a comprehensive presentation of health outcomes and social determinants of health and other factors that contribute to the well-being of children with special needs across the State.

#### E. ASSETS AND GAPS

Section 5, Assets and Gaps, summarizes the preceding components of the CHNA. Assets highlight county information indicating improvement over time, in comparison to other Counties and the State, or in comparison to other races or genders. Gaps focus on disparities in Counties where CSH facilities are located that have a negative trend, in comparison to other counties in the State or to other races or genders.

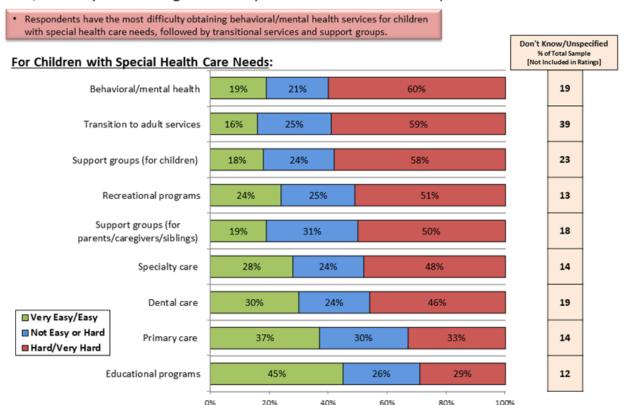
#### **RESOURCE INVENTORY**

A resource inventory is included as **Appendix C**, which details health and social service resources available to residents with children with special health care need. Providers' names, addresses, and phone numbers and type of services provided are contained in the inventory.

#### 3. COMMUNITY HEALTH NEEDS ASSESSMENT SURVEY DATA – SUMMARY TABLES

## A. EASE/DIFFICULTY OF ACCESSING COMMUNITY SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Ease/Difficulty of Accessing Community Services for Children with Special Health Care Needs

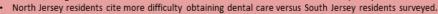


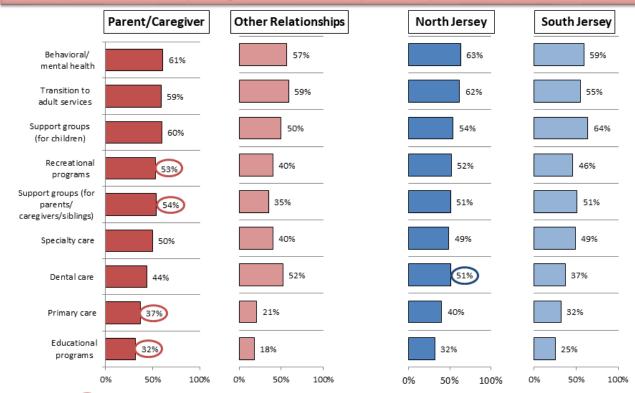
(n=263 Total Respondents) Individual ratings based on those who gave a rating for that service.

Q.3 - Please think about the different types of services and programs that are available in <u>your community</u> for children with special health care needs and their families. How easy or hard is it to access each of the following in <u>your community</u>?

## Ease/Difficulty of Accessing Community Services for Children with Special Health Care Needs ~ Among Subgroups (% Saying "Hard" or "Very Hard")

• Parents/caregivers find it more difficult to access certain services versus "others" (family members or workers with children of special health care needs).





Significantly higher than corresponding group at 90% confidence level.

Individual ratings based on those who gave a rating for that service.

Q.3 - Please think about the different types of services and programs that are available in <u>your community</u> for children with special health care needs and their families. How easy or hard is it to access each of the following in <u>your community</u>?

Volunteered Types of Recreational Programs Would Like to Be More Accessible for Children with Special Health Care Needs ~ Major Mentions

#### **Sports Programs:**

 Team sports/sports for younger children/ swim classes/dance programs/gymnastics/ exercise classes/soccer/yoga/football/ basketball/horseback riding/summer camps/playgrounds

#### **Art Programs:**

 Art therapy/arts 'n crafts/painting/music therapy/drama clubs/cooking classes

#### Social Skills:

 Social skills development/social gatherings/social programs/social activities/play groups/support groups

#### **Programs for Specific Groups:**

 Older children/children with autism/geared toward those with physical disabilities/for those in wheelchairs/early intervention preschool

#### **Program Characteristics:**

 Programs closer to home/programs more affordable/low cost/less expensive/more convenient/better hours/supportive personnel/small group programs/group activities/inclusive programs

#### **General Comments:**

"Everything offered to other children."

Asked of those who gave hard/very hard rating to accessing recreational programs.

Q.4 - You indicated that it was hard to access [RECREATIONAL PROGRAMS] in your community.

What [RECREATIONAL PROGRAMS] would you like to be more accessible in your community?

Volunteered Types of Educational Programs Would Like to Be More Accessible for Children with Special Health Care Needs ~ Major Mentions

#### Improved Subject Learning:

 Reading/writing/math/sciences/more books/tutoring/homework help

#### Better Personnel:

 Better teachers/more competent/more experienced providers

#### Better Equipped Public Schools:

 Better environment in public schools/ more inclusion programs within public school system/more special needs' classrooms/assistance with school issues/more inclusive

#### Easier Access:

 Access to early intervention/more accessible/therapists close by/all programs made accessible/more awareness of options available/less stressful process

#### Focus on Autism:

 Specialized plans for autism/autism services at district level/for those with severe autism

#### **Specific Therapies:**

 Dyslexia program/basic hygiene-puberty classes/neurodevelopment centered programs/programs based on applied behavioral analysis/adoptive learning

#### Geared for Specific Groups:

Older/higher functioning kids/children under 3/focus on those with language disabilities/those who do not have autism/gifted children with disabilities/dual diagnosis of mental/behavioral health/moderate developmental delays/vision therapy/speech therapy/social skills/group social skills/job training/vocational programs/after school clubs/field trips/nature hikes

Asked of those who gave hard/very hard rating to accessing educational programs.

Q.4 - You indicated that it was hard to access [EDUCATIONAL PROGRAMS] in your community.

What [EDUCATIONAL PROGRAMS] would you like to be more accessible in your community?

#### B. BARRIERS TO ACCESSING HEALTH CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

#### Barriers to Accessing Health Care for Children with Special Health Care Needs



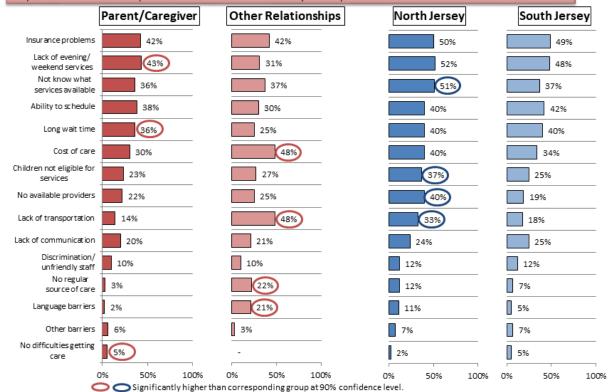
(n=263 Total Respondents)

Q.5a – (Parents/Caregivers) Over the last few years, which, if any, of the following issues made it difficult for you to access health care for your child with special health care needs? (Select all that apply)

Q.5b - (Other Relationship) In your opinion, which, if any, of the following issues do you feel make it more difficult for children with special health care needs to get the health care that they need? (Select all that apply)

#### Barriers to Accessing Health Care for Children with Special Health Care Needs ~ Among Subgroups

- Parents/caregivers cite lack of evening hours and long wait times, while those with other relationships cite cost of care, lack of transportation, no regular source of care and language barriers more often.
- North Jersey residents surveyed cite lack of knowledge about services available, children not eligible for services, no available providers and lack of transportation more than their South Jersey counterparts.



Q.5a – (Parents/Caregivers) Over the last few years, which, if any, of the following issues made it difficult for you to access health care for your child with special health care needs? (Select all that apply)

Q.5b - (Other Relationship) In your opinion, which, if any, of the following issues do you feel make it more difficult for children with special health care needs to get the health care that they need? (Select all that apply)

## C. USEFULNESS OF SPECIALTY PROGRAMS AND SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Usefulness of Specialty Programs/Services for Children with Special Health Care Needs (% Saying Program Is "Extremely" or "Very" Useful)

- Transition to adult services and community recreational programs top the list of the most useful programs for children with special health care needs.
- · While a virtual access facility is rated the lowest, it is still viewed as being very useful to a majority of respondents.

Transition to adult services (job pathways/connections, etc.) 91%

Community recreational programs (martial arts programs, aquatic programs, etc.)
90%

Early developmental screenings 87%

Camps/clubs (recreational overnight/ day camps/clubs) 86%

Peer mentor program 85% Private online portal to access info/schedule appt. 80%

Paralympic sports club 76% Virtual access facility (Skype/Facetime) 60%

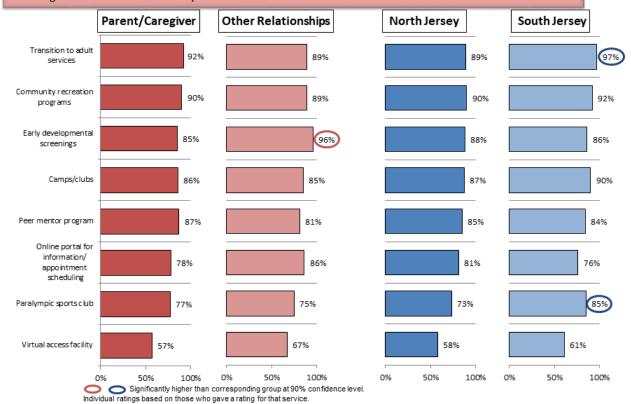
Individual ratings based on those who gave a rating for that service.

Q.6 - Now, think about specialty programs and services offered by facilities in your area that serve children with special health care needs.

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

Usefulness of Specialty Programs/Services for Children with Special Health Care Needs ~ Among Subgroups (% Saying Program Is "Extremely" or "Very" Useful)

 Most specialty programs are seen as very useful to parent/caregivers as well as those with other relationships, throughout the state of New Jersey.

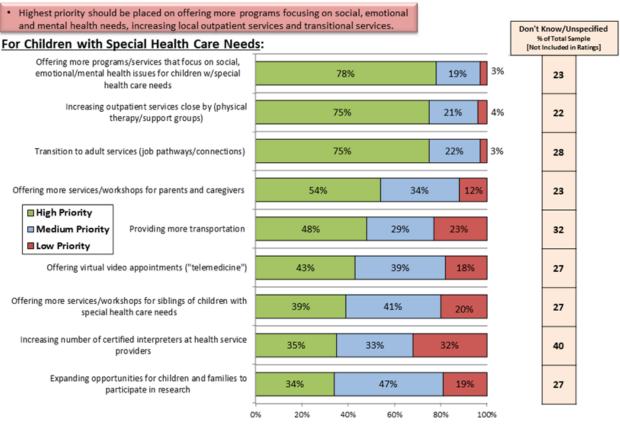


Q.6 - Now, think about specially programs and services offered by facilities in your area that serve children with special health care needs.

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

#### D. PRIORITY OF SOLUTIONS/RESOURCES SERVING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

#### Priority of Solutions/Resources Serving Children with Special Health Care Needs

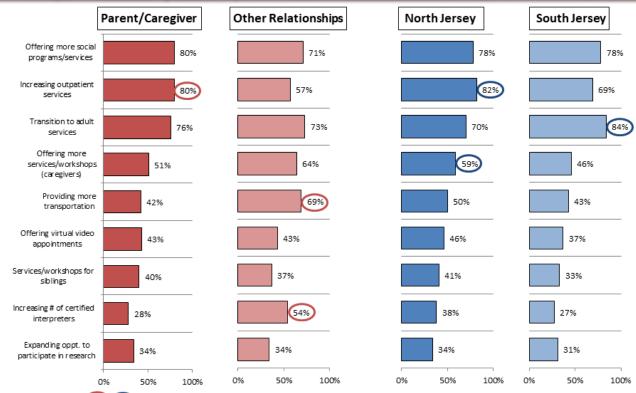


(n=263 Total Respondents) Individual ratings based on those who gave a rating for that solution.

Q.7 - Again, think about facilities that serve children with special health care needs. When deciding about future resources, what priority do you feel these facilities should place on each of the following?

## Priority of Solutions/Resources Serving Children with Special Health Care Needs ~ Among Subgroups (% Saying "High Priority")

Increasing outpatient services are a higher priority to parents/caregivers, while those with other relationships place higher priority
on transportation and increasing certified interpreters.



Significantly higher than corresponding group at 90% confidence level.

Individual ratings based on those who gave a rating for that solution.

Q.7 - When deciding about future resources, what priority do you feel these facilities should place on each of the following?

#### Volunteered Types of Services/Workshops Would Like to See Offered ~ Major Mentions

#### For Parents/Caregivers

- Transitional services/planning for adult life
- Legal services
- Support groups/peer support/sharing resources/emotional help
- Behavior strategies/behavioral health
- Working with school system/navigating IEPs/school requirements
- General education and training
- Navigating insurance
- Financial services
- Social skills
- · Better understanding of autism/services available for autism
- Dealing with ADHD
- · Coping strategies/accepting and coping with diagnosis
- Understanding diagnosis/health care needs/medical information
- Life skills/everyday life
- Stress management
- Social gatherings/recreational programs
- Respite care
- Mental health services
- Support for siblings
- What resources/services are available/how to access services

#### For Siblings

- Coping skills/helping siblings cope/coping with stress
- Peer support/peer groups/support groups
- Activities for siblings/play groups/socialization with others
- Counseling/dealing with their feelings
- Understanding their siblings' condition/learning special needs of siblings
- How they can promote understanding of special needs to others
- Focus on making them feel special/making them know they are not alone

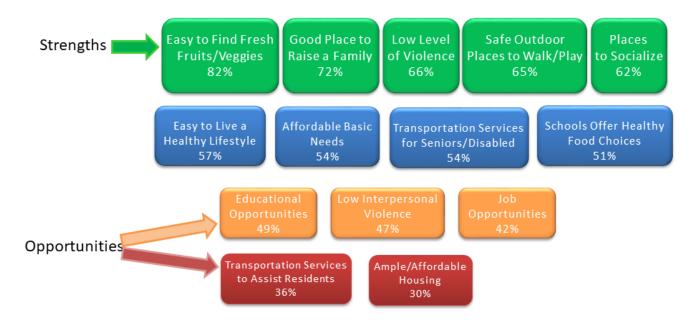
Asked of those who indicated medium/high priority.

- Q.7a You indicated that priority should be given to offering more services or workshops for parents and caregivers of children with special health care needs. Use the space below to specify what types of services and/or workshops you would like to see offered.
- Q.7b You indicated that priority should be given to offering more services or workshops for siblings of children with special health care needs. Use the space below to specify what types of services and/or workshops you would like to see offered.

#### E. STRENGTHS AND OPPORTUNITIES OF COMMUNITY SERVICES OFFERED

## Strengths and Opportunities of Community Services Offered (Top 2 Box Agreement)

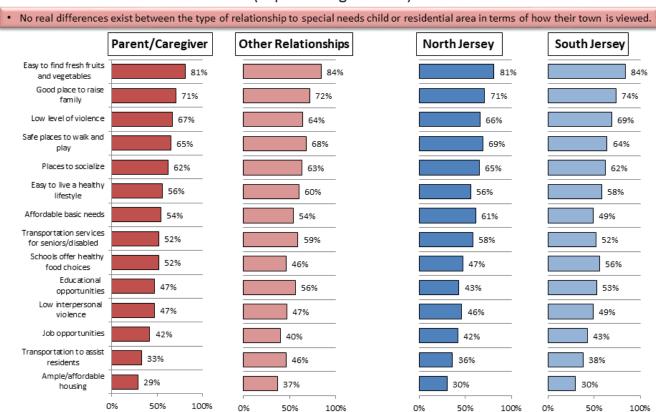
- The large majority of respondents surveyed feel it is easy to find fresh foods in their town, it is a good place to raise a family, there is a low level of violence, there are safe places to walk/play and places to socialize.
- Opportunities exist in the area of affordable housing, transportation services to assist residents, jobs, interpersonal violence and education.



Individual ratings based on those who gave a rating for that service.

Q.8 - Looking to the larger community health issues for the town in which you live, using a scale of 1-5, where 1 = Disagree Completely and 5 = Agree Completely, please indicate how much you agree or disagree with each of the following statements about your town.

## Strengths and Opportunities of Community Services Offered ~ Among Subgroups (Top 2 Box Agreement)



Significantly higher than corresponding group at 90% confidence level.

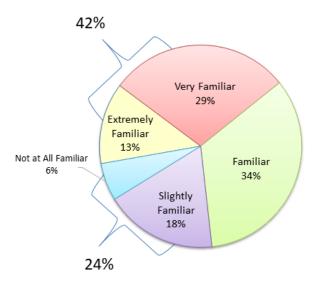
Individual ratings based on those who gave a rating for that service.

Q.8 - Looking to the larger community health issues for the town in which you live, using a scale of 1-5, where 1 = Disagree Completely and 5 = Agree Completely, please indicate how much you agree or disagree with each of the following statements about your town.

## F. FAMILIARITY AND USAGE OF FACILITIES THAT SERVICE CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Familiarity with Facilities that Service Children with Special Health Care Needs

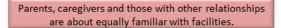
 In all, roughly three-fourths (76%) of respondents surveyed feel they are familiar with facilities that service children with special health care needs.

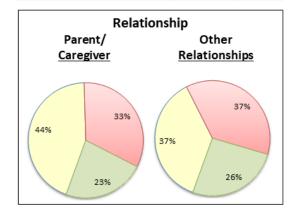


Based on those who gave an answer.

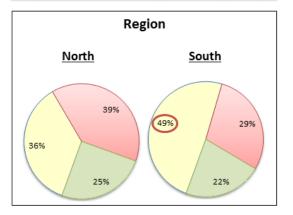
 $Q.10-Please \, rate \, how \, familiar you \, are \, with \, facilities \, that \, service \, children \, with \, special \, health \, care \, needs.$ 

## Familiarity with Facilities that Service Children with Special Health Care Needs ~ Among Subgroups





Respondents in the Southern NJ region are more familiar with facilities than those in the North.



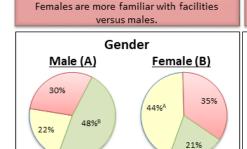


Significantly higher than corresponding group at 90% confidence level. Among those who answered question.

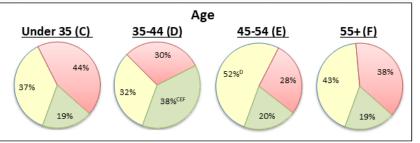
 $Q.10-Please \, rate \, how \, familiar \, you \, are \, with \, facilities \, that \, service \, children \, with \, special \, health \, care \, needs.$ 

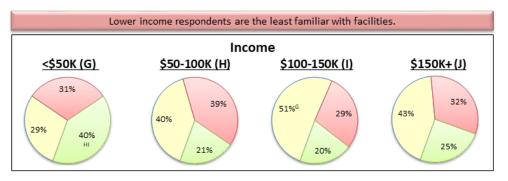
Familiarity with Facilities that Service Children with Special Health Care Needs ~ Among Subgroups - (continued)





Respondents 45-54 years of age appear the most familiar with facilities while respondents 35-44 appear the least familiar.

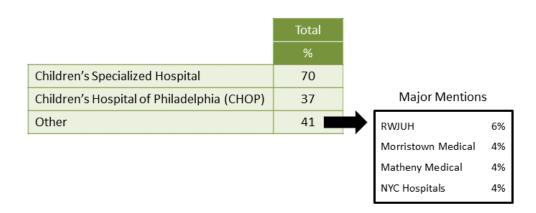




(A/B) (C/D/E/F) (G/H/I/J) = Significantly greater than corresponding group at the 90% confidence level. Among those who answered question.

Q.10 - Please rate how familiar you are with facilities that service children with special health care needs.

#### Usage of Facilities for Children with Special Health Care Needs ~ Major Mentions



Multiple mentions

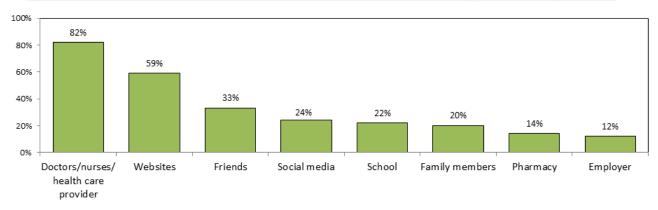
Note: Asked of Parents/Caregivers only (n=196)

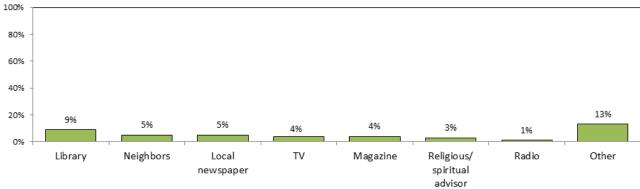
Q.2 - What facilities have you ever used for your child(ren) with special health care needs?

#### G. SOURCES FROM WHICH TO OBTAIN HEALTH CARE INFORMATION

#### Sources from Which Obtain Health Care Information

 Health care professionals are by far the largest source for obtaining health care information, followed distantly by websites, friends, social media, school and family members.





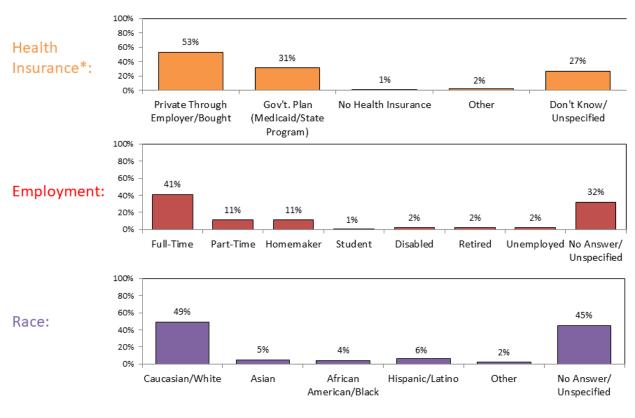
Multiple Mentions

Based on those who answered question.

Q.11 - Of the sources listed below, which do you get most of your health information from? (Select all that apply.)

#### H. DEMOGRAPHICS

#### Demographics



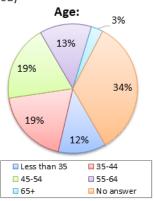
Multiple Mentions (n=263 Total Respondents) \* (n=196 Asked only of Parent/Caregivers)

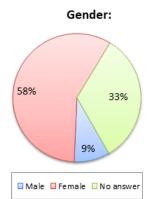
Q.12 - At this time, is(are) your child(ren) covered by health insurance, including private health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

Q.15 - Which of the following best describes your current employment status?

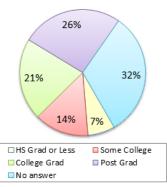
Q.20 - How would you describe your race/ethnicity?

#### Demographics - (continued)

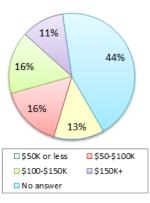




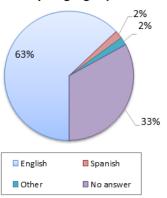
#### Education:



#### Income:



#### Primary Language Spoken:



(n=263 Total Respondents)

- Q.17 Please indicate your age and gender identity.
- Q.18 What is your highest level of education you have completed?
- Q.19 Approximately what is your entire household income before taxes?
- Q.21 What is the primary language you speak at home?

#### I. SAMPLING OF ADDITIONAL VERBATIM COMMENTS

#### Sampling of Additional Verbatim Comments - (Reference Data File for Complete List)



## 4. <u>NEW JERSEY STATE AND CSH COUNTIES HEALTH PROFILE</u> Social and Economic Context of the Region

#### A. DEMOGRAPHICS

CSH operates 13 locations in 9 Counties in New Jersey. The following Table illustrates the statewide population by County. The Counties in which CSH facilities located are shaded in orange. The population of the Counties in which CSH facilities are located range in size from 272,926 (Atlantic County) to 837,288 (Middlesex County).

**Total Populations, State and County, 2013-2017** 

Geography	Population		
New Jersey	8,960,161		
Atlantic County	272,926		
Bergen County	937,920		
Burlington County	449,192		
Camden County	510,996		
Cape May County	94,549		
Cumberland County	154,952		
Essex County	800,401		
Gloucester County	291,372		
Hudson County	679,756		
Hunterdon County	125,717		
Mercer County	373,362		
Middlesex County	837,288		
Monmouth County	627,551		
Morris County	498,847		
Ocean County	589,699		
Passaic County	510,563		
Salem County	63,776		
Somerset County	333,316		
Sussex County	143,570		
Union County	557,320		
Warren County	107,088		

DATA SOURCE: US Department of Commerce, Bureau of the Census, American Fact Finder, 2013-2017 American Community Survey.

The following table shows the racial and ethnic distribution of the State and each New Jersey County. The majority of residents in New Jersey self-identify as white, non-Hispanic (56.1%), followed by residents who self-identify as Hispanic (18.5%), and Black, non-Hispanic (12.7%). CSH serves a diverse communities across the nine counties in which its facilities are located. Ocean County has the highest percentage of residents who self-identify as non-Hispanic White (84.9%). The highest percentage of Essex County residents self-identify as non-Hispanic Black (38.8%). Hudson County has the highest percentage of residents who self-identify as Hispanic (43.2%). The highest percentage of Middlesex residents self-identify as non-Hispanic White (44.3%) followed by non-Hispanic Asian (23.9%).

Racial and Ethnic Characteristics of New Jersey Population by County 2013-2017.

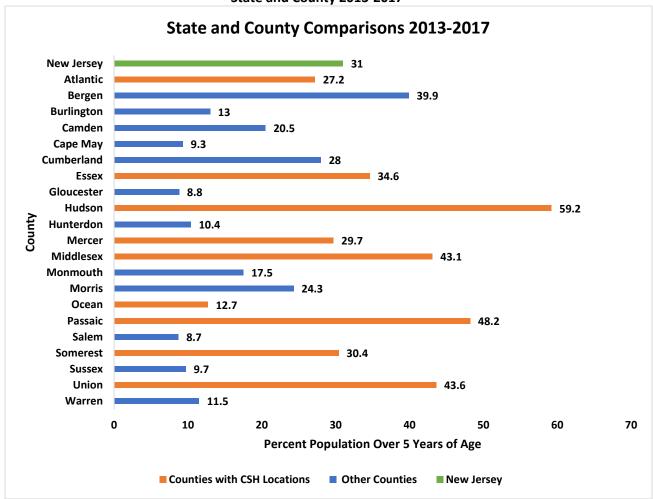
Geography	White, Non- Hispanic	Black, Non- Hispanic	Hispanic any race	Asian, Non- Hispanic	Other, Non- Hispanic
New Jersey	56.1%	12.7%	19.7%	9.4%	2.2%
Atlantic	56.4%	14.3%	18.5%	8.4%	2.4%
Bergen	57.8%	5.3%	18.9%	16.2%	1.8%
Burlington	68.3%	15.7%	7.6%	4.8%	3.5%
Camden	57.5%	18.1%	16.1%	5.7%	2.6%
Cape May	85.6%	4.5%	7.4%	1.0%	1.6%
Cumberland	47.4%	17.7%	29.7%	1.3%	3.9%
Essex	31.1%	38.8%	22.4%	5.1%	2.4%
Gloucester	79.1%	9.9%	5.8%	3.0%	2.1%
Hudson	28.8%	10.8%	43.2%	15.0%	2.3%
Hunterdon	86.3%	2.5%	6.2%	3.8%	1.2%
Mercer	50.8%	19.7%	16.9%	10.7%	1.8%
Middlesex	44.3%	9.3%	20.4%	23.9%	2.0%
Monmouth	75.4%	6.7%	10.6%	5.4%	1.9%
Morris	72.0%	3.0%	13.0%	10.1%	1.8%
Ocean	84.9%	2.8%	9.0%	1.9%	1.3%
Passaic	42.0%	10.6%	40.5%	5.2%	1.6%
Salem	75.1%	13.1%	8.3%	0.9%	2.7%
Somerset	57.7%	9.0%	14.4%	17.0%	1.8%
Sussex	87.2%	2.0%	7.5%	2.0%	1.4%
Union	40.7%	20.1%	30.7%	4.9%	3.6%
Warren	82.9%	4.2%	8.6%	2.9%	1.4%

DATA SOURCE: US Department of Commerce, Bureau of the Census, American Fact Finder, 2013-2017 American Community Survey.

#### Language Spoken at Home in New Jersey

The following figure illustrates that 31% 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 12.7% (Ocean County) to 59.2% (Hudson County).

## Percent Population Over 5 Years of Age Who Speak a Language Other Than English at Home State and County 2013-2017

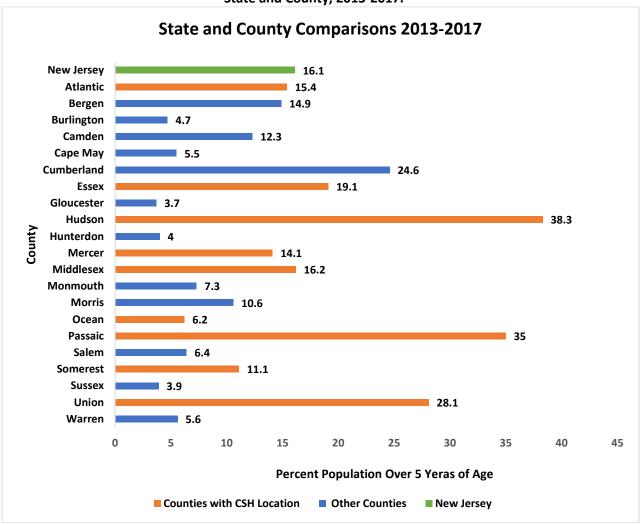


DATA SOURCE: US Department of Commerce, Bureau of the Census, American Fact Finder, 2013-2017 American Community Survey

Families with children in non-English speaking households are less likely report their child's developmental delays, may have difficulty in understanding medical procedures and following medication regimens.

In the State of New Jersey, 16.1% of the overall population speak Spanish at home. In five Counties (Essex, Hudson, Middlesex, Passaic, Union) of the nine Counties in which CSH facilities are located, an equal or higher percentage of the population speak Spanish at home, as in the State of New Jersey.

Percent Population Over 5 Years of Age Who Speak Spanish at Home State and County, 2013-2017.

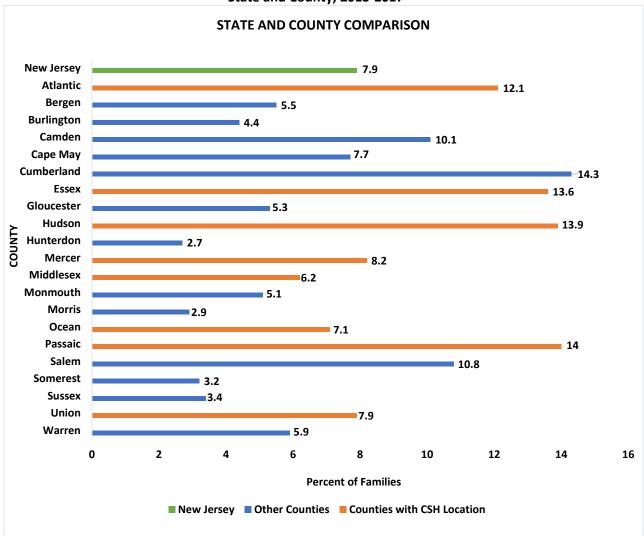


DATA SOURCE: US Department of Commerce, Bureau of the Census, American Fact Finder, 2013-2017 American Community Survey

#### B. 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. The following figure illustrates that overall, 7.9% of families in New Jersey live below the poverty line. Five of the Counties in which CSH facilities are located (Hudson, Essex, Atlantic, Passaic and Union), have a higher percentage of families living below the poverty line compared to the State.

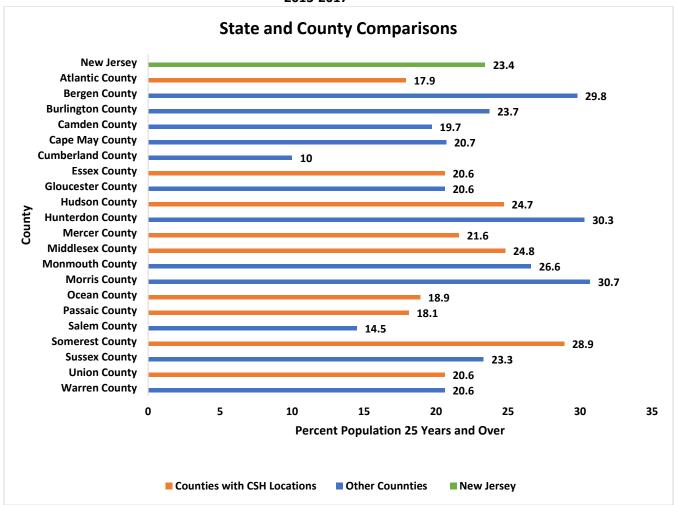
## Percent Families Living Below Poverty Level State and County, 2013-2017



DATA SOURCE: US Department of Commerce, Bureau of the Census, American Fact Finder, 2013-2017 American Community Survey

A parent's education level can impact access to employment and other resources including insurance coverage. In New Jersey, 23.4 % of adults age 25 years and older have obtained at least a Bachelor's Degree. Of the nine counties in which CSH facilities are located, only three counties (Hudson, Middlesex and Somerset) have a higher percentage of adults with bachelor's degree as compared to the sate of New Jersey.

Percent of Adults 25 Years and Older with a Bachelor's Degree 2013-2017

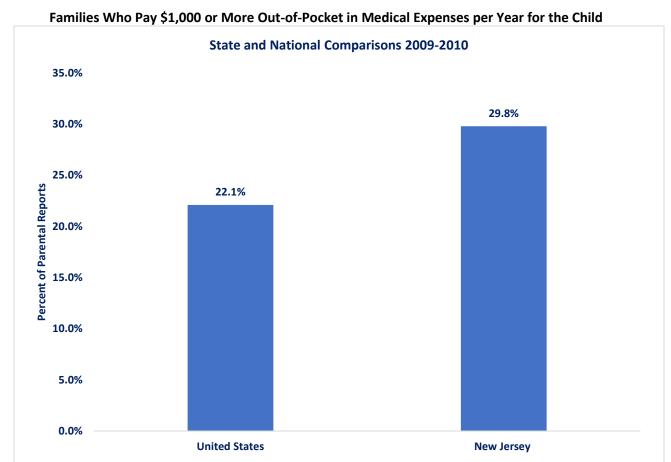


DATA SOURCE: US Department of Commerce, Bureau of the Census, American Fact Finder, 2013-2017 American Community Survey

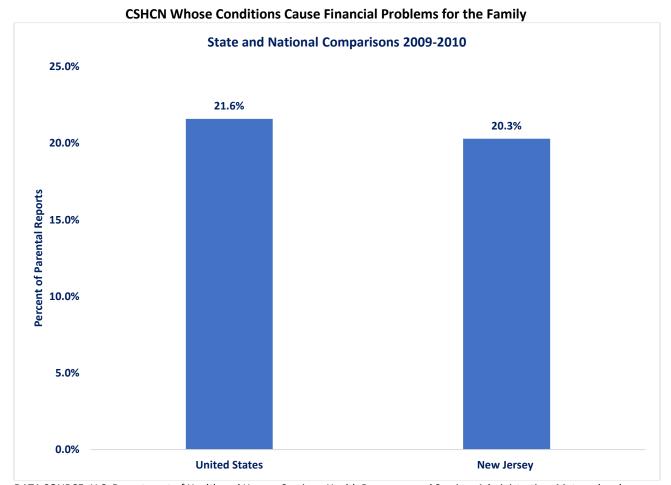
#### **Impact of Families**

Meeting the needs of a child/children with special health care needs (CSHCN) can impact family life in a number of ways. The tables that follow identify and compare the economic impacts on families in the U.S. and New Jersey.

Based on 2009-2010 data, 29.8% of New Jersey parents reported that they pay \$1,000 or more out-of-pocket in medical expenses per year for their special need child compared to 22.1% parents in the United States.

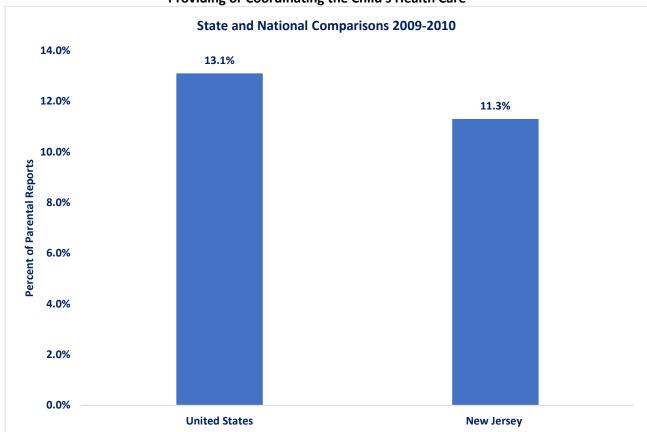


The figure below illustrates that a slightly lower percentage (20.3%) of New Jersey special needs families face financial problems compared to families nationwide (21.6%).

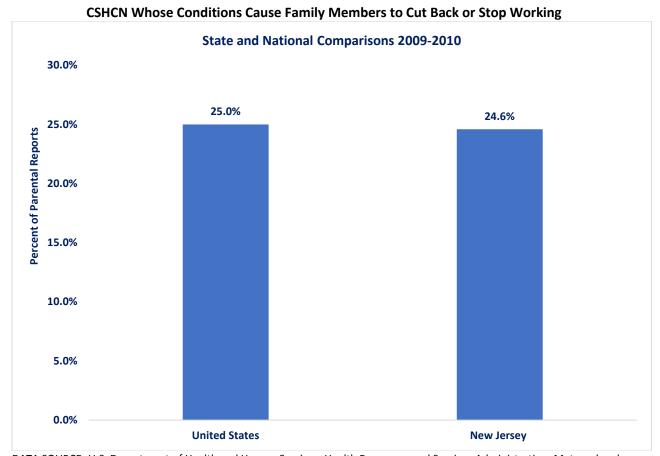


The figure below illustrates that the percentage of New Jersey parents reporting they spent 11 or more hours per week providing or coordinating care for their special needs child's health care is lower (11.3%) in New Jersey than families nationwide (13.1%).

#### CSHCN Whose Family Spends 11 or More Hours per Week Providing or Coordinating the Child's Health Care

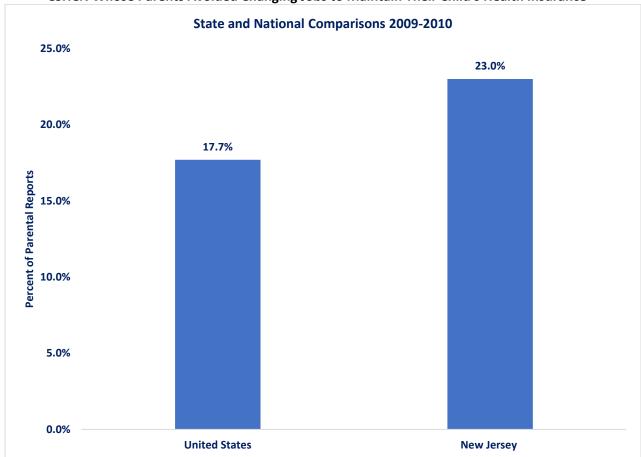


According to 2009-2010 data, a slightly lower percentage (24.6%) of parents in New Jersey report their child's conditions caused family members to cut back or stop working compared to parents in the United States (25.0%).



A higher percentage (23.0%) of New Jersey parents avoid changing jobs to maintain their special health needs child's health insurance compared to families in the United States (17%).

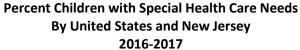


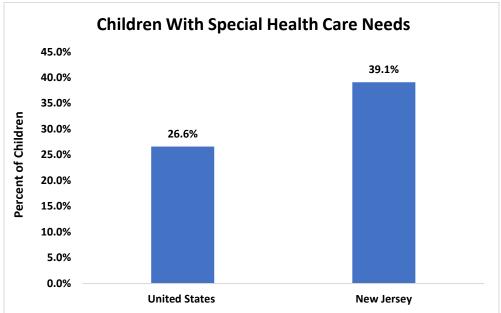


#### C. POPULATION OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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."

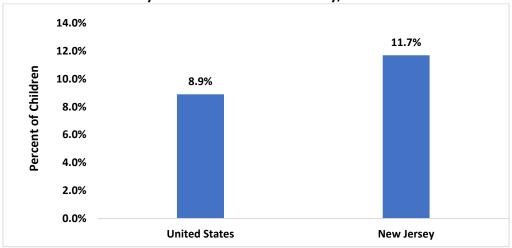
Based on 2016-2017 data, 26.6% of children under the age of 18 in the U.S. overall and 39.1% of children in New Jersey met this definition of having special health care needs. Additionally, a higher percentage of students aged 6-21 received special education services in New Jersey compared to children in the U.S. (11.7% vs. 8.9%).





DATA SOURCE: National Survey of Children with Special Health Care Needs/ National Survey of Children's Health, 2016 – 2017, Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, as cited by Kids Count

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, 2016



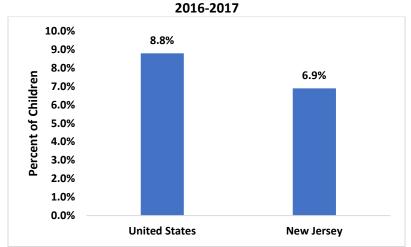
DATA SOURCE: U.S. Department of Education, IDEA Section 618 Data Products, Fall 2015 Individuals with Disabilities Education Act Part B Child Count and Educational Environments as cited by Annual Disability Statistics Compendium 2017

#### Children with ADD/ADHD

According to most recent data from National survey of Children's Health, the rate of ADD/ADHD among children aged 3-17 in New Jersey (6.9%) was lower than the U. S. overall (8.8%).

Percent Children Aged 3 to 17 Years Reported to Have ADD/ADHD

By United States and New Jersey



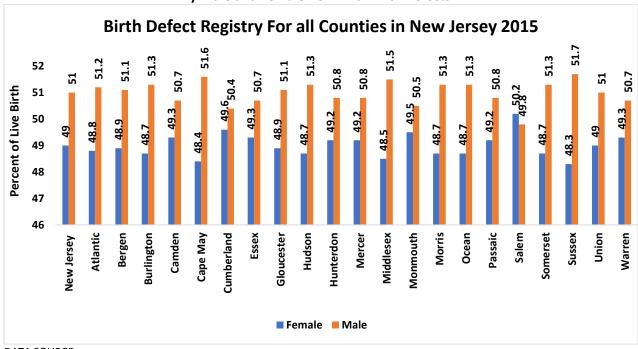
DATA SOURCE: 2016-2017 National Survey of Children's Health, Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health, as cited on www.childhealthdata.org, 2018

#### D. BIRTH DEFECT REGISTRY

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

Data from Birth defects registry of New Jersey shows a higher percentage of birth defects among males than females. Of the nine Counties in which CSH facilities are located, the percent of birth defects among females is higher in Essex, Mercer and Passaic Counties than in the State. The CSH Counties of Atlantic, Hudson, Middlesex, Ocean and Union Counties have higher rates of males with birth defects, than New Jersey.

## Birth Defect Registry For All Counties in New Jersey 2015 By Male and Female Born with Birth Defects



#### DATA SOURCE:

Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health Birth Defect Registry Database, Early Identification and Monitoring Program, Special Child Health and Early Intervention Services, Division of Family Health Services, New Jersey Department of Health.

#### Birth Defects (BD) by Maternal Race/Ethnicity

Following table shows the rate of birth defects by maternal race/ethnicity for New Jersey and each County in the State. It also includes racial/ethnic distribution of the female population of the State and each County. Majority of New Jersey residents self-identify as White, non-Hispanic. Birth defects among whites are highest in the State followed by Blacks, Asians and all other races.

Among 21 counties, Cape May and Salem Counties have a disproportionate percentage of birth defects among Black non-Hispanic mothers as compared to the base population. In Morris County, Asian, non-Hispanic mothers are over-represented in terms of birth defects (14.9%) compared to the base population of Asian, non-Hispanic mothers (11.9%).

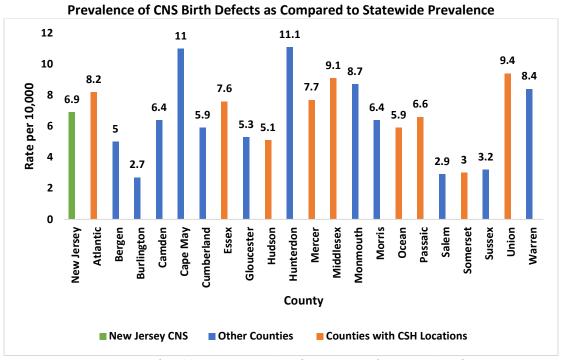
Birth Defects by Maternal Race/Ethnicity in New Jersey 2015, for all Counties

Geography	2015 Total	NJ	White.	White.	Black.	Black.	Asian,	Asian,	All	All
Geography	Population	Population	NH	NH with BD	NH	NH with BD	NH	NH with BD	Other	other with BD
New Jersey	8904413	4561386	69.59	45.5	16.53	14.7	11.84	11.2	2.03	1.9
Atlantic	275376	142159	68.93	42.6	18.42	19.3	10.21	8.5	2.44	1.6
Bergen	926330	478281	70.73	49.2	6.93	5.5	20.56	19.7	1.78	2.2
Burlington	450556	228883	73.95	62.6	17.63	17.6	5.69	6.8	2.73	2.7
Camden	511998	264628	67.99	46.6	22.72	22.2	6.98	5.9	2.30	1.9
Cape May	95805	49188	92.46	75.7	4.39	6.6	1.33	1.5	1.82	1.6
Cumberland	157035	76097	70.15	34.7	23.76	19.3	2.04	1.3	4.04	2
Essex	791609	411387	39.81	21.3	51.28	42.5	6.76	4.9	2.16	1.7
Gloucester	290298	149245	83.66	75.4	11.06	11.8	3.24	3.4	2.05	1.7
Hudson	662619	333415	50.13	26.6	20.41	10.4	26.74	19.9	2.72	4
Hunterdon	126250	63349	91.82	78.8	2.34	1.6	4.38	5.5	1.46	1.1
Mercer	370212	189054	61.02	35.8	24.00	24.8	12.68	10.9	2.30	2.3
Middlesex	830300	421926	55.85	30.5	12.15	9.3	30.05	29.9	1.95	1.7
Monmouth	629185	322985	84.05	63.9	8.11	8.9	6.23	5.6	1.62	1.1
Morris	498192	254118	82.55	62.6	3.71	2.9	11.92	14.9	1.82	1.4
Ocean	583450	303192	93.17	83.6	3.32	2.7	2.23	1.5	1.28	0.4
Passaic	507574	260548	69.83	30.6	18.90	11.4	9.21	5.9	2.06	2.8
Salem	65120	33467	81.36	64.6	15.08	19.4	1.17	1.3	2.40	1.4
Somerset	330604	169352	67.20	45.2	10.94	10.3	19.87	20.8	1.98	1.6
Sussex	145930	73539	94.19	85.7	2.10	2.4	2.24	2.5	1.47	0.7
Union	548744	281481	58.69	31	31.42	21.1	7.80	6.1	2.08	1.2
Warren	107226	55092	90.78	78.8	4.48	4.3	3.17	3.5	1.57	1.4

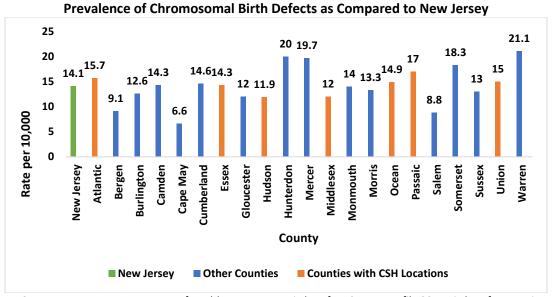
**DATA SOURCE:** US Department of Commerce, Bureau of the Census, American Fact Finder, 2011-2015 American Community Survey, Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health Birth Defect Registry Database, Early Identification and Monitoring Program, Special Child Health and Early Intervention Services, Division of Family Health Services, New Jersey Department of Health.

#### Prevalence of Specific Birth Defects in New Jersey Counties Compared to Statewide Prevalence

The prevalence of Central Nervous System (CNS) birth defects is higher in five CHS Counties (Atlantic, Essex, Mercer, Middlesex and Union) as compared to statewide prevalence of CNS birth defects. The prevalence of chromosomal birth defects is lower in Hudson and Middlesex Counties as compared to other Counties where CSH facilities are located and to the statewide prevalence of chromosomal birth defects.



Data Source: New Jersey Department of Health, New Jersey Birth Defect County Profile 2015 Birth Defects Registry.



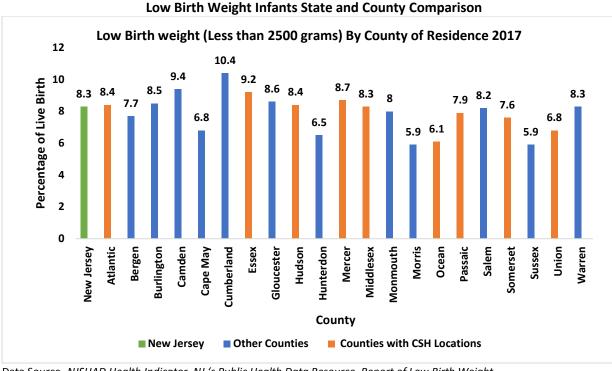
Data Source: New Jersey Department of Health, New Jersey Birth Defect County Profile 2015 Birth Defects Registry.

#### E. LOW BIRTH WEIGHT INFANTS IN NEW JERSEY

Low Birth Weight (LBW) infants may require intensive care at birth and are at higher risk of developmental disabilities and chronic illnesses throughout life. LBW infants have higher health care costs and lengths of stay.

The figure below illustrates that the Cumberland County has the highest percent of LBW infants compared to the State and other Counties. The CSH Counties of Atlantic, Essex, Hudson, Mercer and Middlesex have slightly higher rates of LBW than the State.

Among the nine CSH Counties only four (Ocean, Passaic, and Somerset) have lower rates of LBW infants than the State.



Data Source- NJSHAD Health Indicator, NJ 's Public Health Data Resource, Report of Low Birth Weight

#### 5. ASSETS AND GAPS ANALYSIS

The Assets and Gaps Analysis summarizes and highlights each component of the CHNA. Assets highlight data indicating improvement over time in comparison to other Counties and the State or in comparison to other races and genders. Gaps focus on disparities and have negative trend, in comparison to other Counties and the State.

#### A. ECONOMIC STATUS

#### 1. Poverty and Education

#### **GAPS**

- Overall 7.9% of New Jersey families live below poverty level. The CSH Counties of Atlantic, Essex, Hudson and Passaic have higher percentage families living below the poverty level.
- Atlantic, Essex, Ocean, Passaic and Union Counties where CSH facilities are located have lower percentage of adults with bachelor's degree.

#### 2. Impact on Families those child/children with Special Health Care Needs

#### **GAPS**

- In the State of New Jersey 29.8% of parents with a child/children with special health care needs spend \$1000 or more out of pocket expenses per year for their child compared to 22.1% parents in the United States.
- A higher percentage (23.0%) of New Jersey parents avoid changing jobs to maintain their special health needs child's health insurance as compared to families in the United States (17%).

#### B. BIRTH DEFECTS

#### 1. By Gender and Maternal Race/Ethnicity

#### ASSETS

 Females had lower birth defect rates as compared to males in Counties where CSH facilities are located.

#### **GAPS**

- Of the CSH Counties:
  - Atlantic, Hudson, Middlesex, Ocean and Somerset Counties have higher rates of birth defects among males.
  - Ocean County has highest rate of birth defects among White, non-Hispanic infants.
  - Essex County has highest rate of birth defects among Blacks.
  - Passaic County has the highest rate of birth defects among Hispanic.
  - Middlesex County has the highest rate of birth defects among Asian, Pacific Islander.

#### 2. Low Birth Weight Infants

#### GAPS

- Atlantic, Essex, Hudson, Mercer and Middlesex (Counties in which CSH facilities are located) have slightly higher rates of LBW than the State.
- Cumberland has the highest percent of LBW infants compared to the State and other Counties.

#### C. HEALTH AND HEALTH CARE

#### 1. Survey Results

#### **ASSETS**

- According to survey, children with special health care needs find most specialty programs to be very useful particularly behavioral and mental health services, transition to adult services and support groups for both children and their parents/caregivers/siblings.
- Most residents surveyed are familiar with facilities that service children with special health care needs and the large majority of parents/caregivers have used Children's Specialized Hospital for their child with special health care needs.

#### **GAPS**

- According to survey parents, caregivers and others with a relationship to children with special health care needs found community services and programs are difficult to access.
- Insurance issues, lack of evenings/weekend hours, lack of awareness of services available, scheduling difficulties, long wait and cost of care are all key barriers to community residents with child/ren with special health care needs.
- Only three-fourth (76%) of respondents feel they are familiar with facilities that service children with special health care needs. In addition, respondents from the Southern NJ region are more familiar with facilities than those in the North.
- Males and lower income respondents are the least familiar with facilities.
- Parents and caregivers find it more difficult to access certain services versus "others".
- North Jersey residents cite more difficulty obtaining dental care versus South Jersey residents surveyed.

**APPENDICES** 

#### APPENDIX A: CSH IMPLEMENTATION PLAN RESULTS

## **Children's Specialized Hospital**

# Community Health Needs Assessment 2016-2019

Implementation Plan and Results



#### Introduction

Children's Specialized Hospital (CSH) collaborated with Health Resources in Action to complete the 2016 Community Health Needs Assessment (CHNA). This three month process helped us to identify what we can do to better serve our patients, families, staff, and community.

#### **Method**

- Review of secondary data
- Key Stakeholders
- Online survey responded to by parents



#### <u>Goals</u>

- Determine perceptions of the health-related needs of children with special healthcare needs and their families in our community
- To build upon CSH's 2013 assessment and identify current barriers to accessing health care, as well as gaps/ challenges for kids with special health needs and their families
- To explore opportunities to fill the identified needs and gaps



## Non-English Speaking families have trouble advocating and coordinating care for their children

### Goal 1: Leverage diversity internally and externally to further develop cultural competence

- 1.1: Transition to video interpretation services
- 1.2: Host diversity events yearly at each site
- 1.3: Hire and certify more employees who are culturally diverse and multilingual to assist non-English speaking families





## Children's Specialized hospital needs to lessen wait times and offer more evening appointments

#### Goal 2: Reduce wait times for all services

- 2.1: Explore expansion options at existing sites as well as new site options throughout NJ
- 2.2: Explore alternate care delivery models to increase efficiency
- 2.3: Offer extended hours to alleviate scheduling conflicts









## There is a need for more mental health and other specialty health care providers

## Goal 3: Address mental health complexities and develop an offering focused on children with anxiety disorders

- 3.1: Identify and create partnerships with mental health care providers
- 3.2: Develop signature anxiety program by expanding the existing anxiety short term psychological therapy model at all sites





There is a need to assist families during transition from childhood care to adult care as well as the overall navigation of the health care system

#### Goal 4: Develop care coordination in additional select populations

- 4.1: Implement Care Coordination Program in Special Needs Primary Care Practice
- 4.2: Once successful in Special Needs Primary Care Practice, implement in all Children's Specialized Hospital Programs





There is a need for more recreational services and programs for children with diagnoses other than autism. There is also a need for programs for siblings, families, and caregivers.

**Goal** 5: Consolidate all Children's Specialized Hospital recreation, sports, and other community programs into a single, sustainable program line

- 5.1: Implement the Activity Connection
  - Includes sibling groups and programs designed to meet the needs of children with diagnoses other than autism



5.2: Continue to offer workshops and programs to assist families and caregivers



There is a need for a formal structure of medical and educational providers to communicate to alleviate stress for parents struggling to advocate and coordinate across systems

#### Goal 6: Assist in coordinating between medical and educational providers

6.1: Children's Specialized Hospital will make an effort to increase both the amount and the types of workshops it offers to address these needs



#### **CHIP Achievements**

#### Goal 1

- 1.1: Implemented Video Remote Interpretation at 5 sites
- 1.2: Hosted diversity celebrations at each site
- ${\bf 1.3:} \ Continuing \ to \ work \ towards \ our \ ongoing \ goal \ to \ hire \ and \ certify \ more \ employees \ who \ are \ culturally \ diverse$

#### Goal 2

- 2.1: Expanded our Clifton, Hamilton and Mountainside locations and are exploring new opportunities in Monmouth and Essex County
- 2.2: Implemented new telemedicine programs
- 2.3: Now offering Friday, Saturday, and Sunday appointments at select locations throughout NJ

#### Goal 3

3.1: Created a signature inpatient anxiety program

#### Goal 4

4.2: Implemented care coordination in our Chronic Illness Management Program and Chronic Pain Management Program

#### Goal 5

- 5.1: Created the Activity Connection with houses over 40 recreational programs for patients and their siblings
- 5.2: Offered programs like Managing Your Child's Behavior, Navigating Your Child's Journey, and support groups for parents and caregivers

#### Goal 6

6.1: Developed new workshops for families to help coordinate between medical and educational providers such as Navigating Crucial Transitions from Elementary to Middle School



## Challenges and Barriers Encountered

- Our community is not our immediate community
- Limited clinical staffing pool
- Changes in Medicaid and CHIP





#### **APPENDIX B: SECONDARY DATA SOURCES**

Source			
American Fact Finder/ACS	https://factfinder.census.gov/faces/nav/jsf/pag index.xhtml		
U.S. Department of Health and Human services	https://www.hhs.gov/programs/index.html		
BRFSS and Youth BRFSS	www.cdc.gov		
CDC	http://www.cdc.gov		
CDC Community Health Indicators Service	http://wwwn.cdc.gov/CommunityHealth		
National Survey for Children's with Special Health Care Needs	https://www.childhealthdata.org/browse/s		
	<u>vey</u>		
NJ Department of Health	https://www.nj.gov/health/public/index.shtml		
Bruno and Ridgway Community Health Assessment Study			
NJ Birth Defects Registry	https://www.nj.gov/health/fhs/bdr/		
NJSHAD Health Indicator	https://www-doh.state.nj.us/doh- shad/query/selection/birth/BirthSelection.html		
New Jersey State Information	https://en.wikipedia.org/wiki/New_Jersey		
U.S. Department of Education	https://www2.ed.gov/programs/osepidea/618- data/state-level-data-files/index.html		
National Survey of Children with Special Health Care Needs Chartbook	https://mchb.hrsa.gov/cshcn0910/state/pages/nj html		
State of New Jersey Department of Health, Autism	https://www.state.nj.us/health/fhs/autism/		

#### APPENDIX C: RESOURCE INVENTORY

Name	Name Services		Website		
Greater Metro West ABLE'S	Local Jewish organizations	Essex, Morris, Somerset, Sussex and Union	https://www.greatermetrowestable.org/?ut m_source=Kveller&utm_medium=ABLE- resource-page&utm_campaign=GMWABLE		
SPAN (Statewide Parent Advocacy Network)	Guide to developing and conducting an effective group	Newark, NJ			
Cambridge School	specialize in educating students with dyslexia, ADHD, and other language-based learning disabilities	Pennington, NJ	https://www.thecambridgeschool.org/contact-us/		
The Midland School	Helping students with disabilities reach their highest potential	North Branch	https://midlandschool.org		
Deron School of New Jersey, Inc	School prepares children with disabilities to lead successful, productive lives help to communicate in the community	Deron I Union, NJ Deron II Montclair, NJ	https://www.deronschool.org		
The Arc of Essex County	Provides services for people with intellectual and developmental disabilities and their families	Livingston, NJ	https://arcessex.org		
Bethel Ridge	Sharing service by conducting classes for people with special needs to provide greater opportunities for kids	Basking Ridge, NJ	https://bethelridgenj.org/J3/		
Children's Center at Monmouth County	Serving the special need for children and their families	Neptune, NJ	http://www.ccprograms.com/ContactUs.asp x		
Special Kids Fun (SKF)	SKF is a unique charity alliance of social service organization, hospital, camps and schools caring for developmentally disabled children and youth.	Lakewood, NJ	http://www.specialkidsfund.org		
New Jersey Institute for Disabilities	NJID offers specialized facilities, programs and supports throughout the state of New Jersey for children and youth	Edison, NJ	https://www.njid.org/children-programs		
NJ Children's System of Care Contracted System Administrator-Perform Care	Helping families across the state for Behavioral health, Intellectual/developmental disability services and substance use services	Robbinsville, NJ	https://www.performcarenj.org/index.aspx		

Name	Services	Locations	Website
Easterseals New Jersey	Non-profit organization that helped children and adults with disabilities and special needs, live better lives for nearly a century	East Brunswick, NJ	https://www.easterseals.com/nj/who-we- are/contact-us/
United Cerebral Palsy (UCP) of Hudson County	UCP provides services to people with disabilities and it helps them to improve the independence, productivity and quality of life.	Bayonne, NJ	http://ucpofhudsoncounty.org/about-us/
Lardacein Network	It is a non-profit agency provides continuum of care including educational, therapeutic, social, residential and support services to infants, children and adults with complex physical and developmental disabilities or delays.	Wanamassa, NJ	https://www.ladacin.org
Hudson Milestone	Provides in-home respite and early intervention services for families and children with developmental disabilities	Jersey City, NJ	http://www.hudsonmilestones.org/contact- us/
Autism New Jersey	It is a non-profit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them.	Robbinsville, NJ	https://www.autismnj.org/connect/contact- us/
Need Quest	Local directory of special needs resources for parents, children and families in New Jersey	Westfield, NJ	https://needquest.com/contactus
Youth Consultation Service (YCS)	YCS Sawtelle services provides educational, inhome, and residential care for individuals with intellectual and developmental disabilities from birth through adulthood.	Newark, NJ	http://www.ycs.org/index.php/contact-us/
New Jersey Alliance for Children, Youth and Families	NJACF collaborate to ensure brighter futures for children, youth and families	Hamilton, NJ	http://njacyf.org/about-us
New Jersey Children System of Care (CSOC)  Provides volunteer services for children through Perfor Care, Contracted Service Administrator for CSOC		Hamilton, NJ	https://www.mercerresourcenet.org/about/ about-new-jersey-s-children-s-system-of- care-csoc/
Princeton Child Development Institute (PCDI)	Providing Lifelong Services to People with Autism	Princeton, NJ	http://pcdi.org/early-intervention/

Name	Services	Locations	Website
Association for Special Children and Families (ASCF)	ASCF is a community-based organization for families of children with disabilities	Hewitt, NJ	https://ascfamily.org/category/contact-us/
The Arc of New Jersey	State's largest organization advocating for serving children and adults with intellectual and developmental disabilities and their families.	North Brunswick, NJ	https://www.arcnj.org/index.html
First Children Services	Life changing outcomes for Exceptional Kids. Educate students with multiple disabilities	Fanwood, NJ	https://www.firstchildrenservices.com/abou t-us/contact-us/
Parents of Autistic Children (POAC) Autism Services	Help children and adults with autism to achieve their fullest potential by providing quality training, support and recreation	Brick, NJ	https://www.poac.net
Autism Spectrum Education Network (ASPEN)	ASPEN provides families and individuals who lives are affected by Autism Spectrum Disorders and Nonverbal learning disabilities	Edison, NJ	https://aspennj.org/contact-aspen
Autism Speaks	Autism Speaks Enhances lives today and is accelerating a spectrum of solutions for tomorrow	Princeton, NJ	https://www.autismspeaks.org/contact-us
Noah's Ark Institute	Noah's Ark Institute is a non- profit organization and is a project of the National Association for Children with Autism	Fairfield, NJ	http://www.noahsarkinstitute.org/contact.h tml
ASAH	ASAH has served private special education schools and agencies in New Jersey ensuring highest standards services excellence for students and youth with disabilities.	Hamilton Square, NJ	https://www.asah.org/contact-us/
School of Children with Hidden Intelligence (SCHI)	SCHI provides educational and therapeutic services by certified professional staff to children with disabilities.	Lakewood, NJ	https://www.schischool.org/contacts/
Harbor School	Providing an alternative program to the public-school districts for students with disabilities.	Eatontown, NJ	https://harborschool.com/contact-us/
Shore Center for Students with Autism	Program of the Bayshore Jointure Commission, is a New Jersey public school placement for students with special needs	Tinton Falls, NJ	https://www.theshorecenter.org/Page/1

Name	Services	Locations	Website
Hawks wood School	Provides high quality special education services to children with complex, multiple disabilities, including autism	Eatontown, NJ	http://hawkswoodschool.net/contact-us/
New Road Schools of New Jersey	Private school for students ages 5-21 years with developmental, learning, social, behavioral and language disabilities.	Perlin, NJ Somerset, NJ Lakewood, NJ	http://newroadschool.com/contact-nrs/
Special Dragons	Providing exercise and self- defense programs for Special Needs Students	Northern New Jersey	http://www.specialdragons.us/index.html
Oakwood School	Private school for disabled children forms ages 11-21 years	Tinton Falls, NJ	http://oakwoodschool.net/contact/
CPC Behavioral Health Care	CPC is a provider of choice for mental health, substance use and special education services for children and their families	Neptune, NJ	https://www.cpcbehavioral.org/neptune
Rugby School	Provide a nurturing environment for special students to maximize their potentials while exploring their unique abilities	Wall Township, NJ	http://www.rugbyschool.org/our- school/about-rugby-school/
Alpha School	School provides educational, therapeutic and support services for students ages 5- 21 with special needs	Jackson, NJ	https://alphaschool.com/contact-us/
Acdemy Learning Center	Center offers comprehensive programing for Students with Autism or Multiple Disabilities from ages 3-21	Monroe, TWP	https://www.escnj.us/domain/110
Puzzle Place center For Autism	A Playful Approach to Serious Therapy	Freehold, NJ	https://thepuzzleplace.org/our-approach/
Devereux Advanced Behavioral Health	Help to changes lives by unlocking and nurturing human potential for people living with emotional, behavioral or cognitive differences.	West Deptford, NJ	http://www.devereux.org/site/PageServer? pagename=centers
Archway Programs	Provide Step by Step is communication to creating partnerships with children and families to foster and encourage the development of infants and young children with developmental delays.	Atco, NJ	https://www.archwayprograms.org/contact-locations
Community Access Unlimited (CAU)	Provide services for youth with intellectual and developmental disabilities	Elizabeth, NJ	http://www.caunj.org/?page_id=190