CHILDREN'S SPECIALIZED HOSPITAL

COMMUNITY HEALTH NEEDS ASSESSMENT

JUNE 2013

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EXECUTIVE SUMMARY

Children's Specialized Hospital is the only fully-integrated, non-profit comprehensive pediatric rehabilitation facility in the State of New Jersey. Its basic, core mission is to provide programs and services that improve the health and well being of children with special needs. It is unique in that it does not define its catchment area by a handful of zip codes but rather views its mission to serve children throughout the state of New Jersey.

In its commitment to offer programs and services of the highest quality, CSH undertook a Community Health Needs Assessment. This process allowed CSH to take a leadership role in identifying met/unmet needs of those "communities" that use or may use CSH's services.

Specific objectives of the needs assessment were to:

- Understand the health status of residents of communities served by Children's Specialized Hospital using available public and proprietary data sources.
- Evaluate service utilization patterns and suggestions for service development based on detailed quantitative and qualitative information.
- Identify gaps in the service continuum and devise high quality, cost-effective strategies to fill them.
- Work collaboratively with community organizations and agencies to jointly devise short-term and long-term strategies to develop programs and services that will better meet the needs of the patient populations served by CSH.
- Assist with effectively communicating results, recommendations and strategies to constituents throughout the community.
- Provide detailed data to aid in the completion of the Patient Protection and Affordable Care Act (PPACA) requirements and IRS Schedule H of the Form 990 (Community Benefit Standards).

Methodology Overview

The following components were undertaken for this Community Health Needs Assessment:

COMMUNITY-SPECIFIC HEALTH DATA ANALYSIS

- General demographic information such as income, race, ethnicity, education, etc. were analyzed to develop an overall picture of each community associated with Children's Specialized Hospitals and outpatient facilities.

- Information from CSH's proprietary databases was used to assist in generating a report regarding the populations that are utilizing its services. CSH also provided data including: discharges by diagnosis or product line; patient demographics, insurance status and origin, among other demographics.

- CSH provided to AMK county health profiles produced by NJHA's Health Research and Education Trust for all counties in New Jersey.

KEY INFORMANT INTERVIEWS

- Four Key Informant Interviews were conducted and included two staff members of CSH, a Board member of CSH and a representative from a health plan that works with CSH. Information regarding the successes and challenges faced by CSH, service utilization and needs, as well as gaps and service suggestions were gleaned from these interviews.

- Despite several attempts, several of the recommended key informants were not available or were simply not responsive.

- AMK conducted telephone interviews approximately 30 – 45 minutes in duration.

- Interviews were analyzed for key issues and commonality of response.

FOCUS GROUPS

- Two focus groups were held. One focus group consisted of CSH physicians and the other was parents who are members of CSH's Family Advisory Council.

- The focus group with physicians lasted approximately 30 minutes while the focus group with parents lasted an hour. .

- AMK facilitated the focus groups.

- Feedback received from participants was analyzed and responses formulated into recommendations.

SURVEYS

- Two surveys were administered using the Survey Monkey on-line system.

- Participants received a letter in advance of the survey asking that they, or whomever they designate, complete the on-line survey. A modest stipend was provided.

- One focus group was comprised of referring physicians and they were provided with a $50 stipend.

- One focus group focused on teachers. A letter was sent to the principal requesting he/she identify the most appropriate person to complete the on-line survey. A $25 stipend was provided.

- Responses to surveys were analyzed for commonality of responses. Detailed comments were used for the development of recommendations.

Summary of Key Findings and Recommendations (see report for complete information)

- There was consensus by those participating in the Parents Advisory Council focus group that there needed to be support for the whole family. A more holistic approach to treatment where the needs of the family can also be addressed. Develop communication tools to distribute to all families regarding support programs and/or services for families, such as "Family Faculty."

- Parents expressed frustration with the lack of communication and coordination of their child's care. Physicians clarified that there is a team-managed/coordinated care for inpatient, however, it is more challenging for outpatients. A strategy for greater and more coordinated communication among all providers treating the patient should be developed. Feedback and suggestions should be solicited from parents as well as referring physicians. A lack of feedback from CSH was raised as an issue by referring physicians.

- Pediatricians play a critical role in referring children with special needs to CSH. A survey administered to referring physicians indicated there was a high regard for the services provided by CSH and clearly an awareness of the services CSH offers. However, this was a relatively small sample and the more challenging group are those pediatricians that are not referring children either because they are not aware of CSH and its services or they are aware, but are not inclined to refer to CSH (for whatever reason).

- Two approaches to better education should be considered:

  - Develop a curriculum that could be offered for Continuing Education Credits at state conferences.

  - Recognizing that physicians must attain a specific number of CEUs to maintain their licenses, the Medical Society of New Jersey often offers programs for Continuing Education Credits. Partnering with the Medical Society of New Jersey to develop and offer courses regarding medical care for children with special needs may allow CSH to reach a much larger community of physicians.

- The Physician Focus Group as well as one Key Informant noted that there was a scarcity of pediatric neurologists which, in turn, resulted in demand far exceeding the supply of this specialized care needed and requested by families.

- When analyzing financial data, it was apparent that many patients were not identified by a race or it was simply noted "unknown." To ensure a true and accurate picture of the patients being served by CSH, training for intake staff should be considered.

- Hudson, Passaic and Union counties have a relatively large population of Hispanics and Latinos. A concern was raised by a parent at the Parents Advisory Council Focus Group session that there were not enough resources or responsiveness to the Hispanic population. CSH now has an opportunity to reexamine the various literatures that are available in Spanish and ensure the availability of interpreters to meet the needs of this population

- There were several counties that had particularly high numbers of children with disabilities; however, there was not a CSH site of service within these areas. It is not realistic for CSH to provide programs and services in every county; however, it should be examined more closely to ensure that those children residing within those counties, (i.e., Essex and Camden) have access to CSH services, particularly when transportation and financial resources are limited

- Within specific geographic areas, there were noticeably high numbers of Asians and yet the numbers served by CSH were remarkably low. What is not clear is whether this particular population experience significantly lower numbers of children with disabilities and special needs than others, such as whites and African Americans. This should be explored in greater depth.

- It was mentioned by a CSH physician that a strategic planning process is under way. The recommendations referenced above should be taken into consideration during that process. If some of the recommendations have already been addressed, then a communication plan

should be developed to share this information with community providers, i.e., services now offered in Newark.

- Referring Physician Recommendations: The following reflect a couple of the more substantive recommendations made by referring physicians and should be given consideration by CSH:

  - Accept cognitively impaired young adults over the age of 18.

  - Further development of a comprehensive adolescent inpatient chronic illness program that would include family therapy, psychiatry, medical/rehab/education with a transition piece and follow-up on discharge.

PHYSICIAN COMMUNICATION/FOLLOW-UP

There were numerous issues and/or concerns raised by referring physicians regarding the lack of information that was provided regarding the patients they referred. More specifically, physicians requested CSH focus on providing progress reports/status updates and an EMR or chart for transfer.

A standardized system of documentation and distribution should be developed to ensure that referring physicians are receiving complete information regarding the patient that is referred. Part of this system should allow for periodic updates when appropriate.

NURSING CARE

There were several comments regarding nursing care at CSH, for example, some parents reported to their physician that they felt nursing staff are not as responsive on the weekends. This information should be provided as feedback and used as an opportunity for discussion and/or additional training.

CAPACITY

Given the feedback provided by parents and referring physicians, demand for CSH services far exceeds supply. This is demonstrated by parents reporting an eight week waiting period for an evaluation. Physicians also reported that there are times when they cannot get a bed for their patient, however, it was also noted that if it was critical, CSH was accommodating.

There should be a review of the availability and feasibility of offering services in other geographic areas. Based on the findings in the charts included in this report, there appear to be specific counties/cities where there are a significant number of children with disabilities (one or more). It is not clear if these children are able to access care from other providers or are simply going without care.

ASSISTANCE WITH MANAGED CARE

Both parents and referring physicians noted the challenges they face in trying to arrange for services when interacting with the managed care companies. Some parents noted that it was complex and they didn't fully understand how the process worked. Some physicians expressed frustration with the referral process and wanted CSH's help when working with the insurance companies.

Through its managed care staff, CSH should consider providing support to parents to help them understand how to navigate the managed care system. Further research should be considered to determine what specific problems or challenges physicians are encountering when attempting to arrange for a referral.

CONCLUSION

The findings from this assessment were expansive and rich in that there are many steps that can be taken to address gaps and unmet needs as well as CSH having the opportunity to drill down for more detailed information and feedback from which to determine how to continue to improve upon the programs and services it offers to children with special needs.

INTRODUCTION

In the fall of 2012, Children's Specialized Hospital (CSH) undertook a community health needs assessment, the purpose of which was to identify unmet needs in the communities it serves. This initiative also provided an opportunity to affirm that the programs and services it currently offers are truly meeting the needs of children with chronic conditions and special needs. This assessment is unlike any other in New Jersey in large part because CSH does not define its community by primary and secondary catchment areas. CSH's mission is to serve children with special needs throughout the state of New Jersey.

Also of distinction is that Children's Specialized Hospital (CSH) is the only fully integrated, non-profit comprehensive pediatric rehabilitation facility in the State of New Jersey. Demand for such services continues to significantly grow. Recognizing this ongoing need, CSH continues to examine the appropriate locations to expand its services and do so even in the absence of sufficient funding.

The information included in this report will provide the foundation from which additional, more detailed data and information can be gathered, however, absent additional research, there is sufficient information to allow CSH to make decisions regarding its current programs and services, to identify areas for improvement and determine if additional programs and services will benefit children with special needs.

GOALS AND OBJECTIVES

The overall goal for Children's Specialized Hospital (CSH) is to provide detailed information about the health status and needs, both met and unmet, of the "communities" that use or *may* use CSH's services. Specific objectives of this needs assessment are to:

- Understand the health status of residents of communities served by Children's Specialized Hospital using available public and proprietary data sources.

- Evaluate service utilization patterns and suggestions for service development based on detailed quantitative and qualitative information.

- Identify gaps in the service continuum and devise high quality, cost-effective strategies to fill them.

- Work collaboratively with community organizations and agencies to jointly devise short-term and long-term strategies to develop programs and services that will better meet the needs of the patient populations served by CSH.

- Assist with effectively communicating results, recommendations and strategies to constituents throughout the community.

- Provide detailed data to aid in the completion of the Patient Protection and Affordable Care Act (PPACA) requirements and IRS Schedule H of the Form 990 (Community Benefit Standards).

METHODOLOGY

This section provides a brief overview of each task that was included in the needs assessment.

County-Specific Data Analysis

Data sources include demographic, utilization and financial and primary (qualitative) data. CSH does not have a defined community as it serves children throughout the state of New Jersey therefore all 21 counties were examined:

- General demographic information such as income, race, ethnicity, education, etc. were used to analyze and develop an overall picture of communities associated with Children's Specialized Hospitals and its satellite facilities.

- CSH provided its most current proprietary financial data regarding utilization for existing CSH service areas. In addition, payer data was also used to provide a general picture of payer mix.

- Primary Data is data collected directly from a source. This process can include key informant interviews, focus groups and surveys, among other strategies. These three processes were used to collect primary data.

Key Informant Interviews

Four Key Informant interviews were conducted. Informants were identified and recommended by CSH leadership and included a diverse group of individuals that had a working relationship with CSH, were employed by CSH or served voluntarily with CSH.

Focus Groups

Two focus groups were convened, one with parents from CSH's Parents Advisory Council which met at CSH's Quakerbridge site, and one with hospital-based physicians. Each group was comprised of approximately 12 - 14 participants. .

Surveying

In 2012, CSM conducted a survey – Family Centered Care Survey – that had previously been administered in 2004 and 2008. CSH staff, as well as families that had used CSH services, were surveyed to assess their perceptions of programs, supports and services.

Two groups were surveyed using an on-line survey tool (Survey Monkey). The two groups surveyed were recommended in the course of a Focus Group discussion with CSH's Parents Advisory Council. Schools and referring physicians from the community received surveys. The school survey, which was completed primarily by teachers is included in Appendix C. Responses from the teachers are incorporated into the overall finding at page 53 and physician responses have been incorporated into the overall survey findings that begin on page 61.

KEY FINDINGS

Utilization and Financial Data

The most current utilization data for existing CSH service areas was used including utilization by age, by location and by race. In addition, proprietary payer data was used to provide a picture of payer mix and demonstrate the financial challenges that CSH faces in meeting the needs of children with special needs.

Demographic data

Demographic data provides a picture of the people and the conditions under which they live within geographically-defined areas; in this case, county-level data was used. Because CSH does not have a defined community, data includes all 21 counties in New Jersey and delineates the counties in which CSH has services. Data utilized originated from the New Jersey Hospital Association's Health Research and Educational Trust of New Jersey. Comprehensive County Health Profiles were developed for New Jersey's 21 counties and more than sixty sources were used in the development of each county profile.

Primary Data

Primary data, also known as qualitative data, is collected from an original source. It can be collected via interviews, focus groups, surveying, among other means. Several methods were used to collect primary data including key informant interviews, surveys and focus groups

UTILIZATION AND FINANCIAL DATA

As of 2011, Children's Specialized Services served 17,516 children in the following areas:

Bayonne..... ..... Outpatient
Clifton..... ..... Outpatient
Egg Harbor Twp..... ..... Outpatient & Physician Services
Fanwood..... ..... Applied Behavioral Analysis
Mountainside..... ..... Outpatient & Physician Services
New Brunswick .... Inpatient & Outpatient
Roselle Park .... Medical Day Care
Toms River – Stevens Road..... Outpatient & Physician Services & Long Term Care
Toms River – Lakehurst Road..... Outpatient Services

Utilization Data by Age

Data by age cohort was reviewed to determine the locations that were used by certain age groups along with the services that were most used by specific age cohorts. The following reflects those findings:

Ages 0 – 3 Years

A total of 2,223 children between the ages of zero to three years of age were seen by CSH. The greatest percentage (47.2) of this age group utilizes Medical Day Care services in Roselle Park followed by inpatient and outpatient services (25.6 percent) in New Brunswick. With more data, a more detailed breakdown of utilization of New Brunswick Services can be determined.

Ages 4 – 10 Years

This age group represents the largest percentage of children being treated at all sites. The sites that treat the greatest numbers include:

Facility	Service	Children Served
Mountainside	Outpatient and Physician Services	3,900
Toms River*	Outpatient, Physician Services and Long Term Care	2,300
Hamilton	Outpatient and Physician Services	1,700

The 4-10 age group comprises the largest percentage of children served at Bayonne and Clifton with 66.3% and 61.6% respectively.

Ages 11 – 15

The majority of this age cohort received its services at Mountainside. However, 24.4 percent of this cohort used the Hamilton site and 24.3 percent of this cohort utilized services at Toms River.

Ages 16+

A total of 2,431 children in this age group were served by CSH. Of this age group, Mountainside served the largest number with 1,324 children. The 16+ age group comprised the largest percentage of children served at the Fanwood location and had approximately 24 percent of the visits in New Brunswick.

Utilization Data by Race

When examining utilization by race, it is interesting to note that of the 17,516 children served, 3,288 are reported as "Other Races" while 279 are reported as "Unknown" race. These are relatively high and it would be interesting and helpful to truly examine if upon intake the family indicates "Other" or "Unknown" or if additional training for intake staff would significantly reduce these figures. There were 77 reported as having declined to answer.

The numbers associated with "Other Races" or "Unknown" are relatively large numbers. Mountainside appears to account for 2,050 of these two categories. Should a more in-depth analysis be conducted by CSH reviewing the numbers of minorities and those of other races within counties in relation to those served by CSH, the numbers within a county relative to the numbers served by CSH absent having an actual racial identification can distort the demographic profiles of those truly being served.

The majority of the 17,516 children served fall under the following races:

Reported Race	Number of Children Served
White	10,528
Black/African American	2,491
Asian/Indian	317
Multiracial	172
Other Asian	148
Chinese	81

Other races included are:

Filipino	Native Hawaiian
Guamanian or Chamorro	Pacific Islander
Japanese	Samoan
Korean	Vietnamese

Reimbursement/Insurance/Payer Mix

There are numerous insurers that provide reimbursement to CSH. For the purposes of studying payer mix, only those Payers that are licensed to operate in the state of New Jersey and cover a more significant number of clients served by CSH will be referenced in the Payer Mix analysis.

The following Health Plans are licensed under New Jersey's Department of Banking and Insurance to provide managed care to the general population. Of these plans, four provide managed care to only Medicaid recipients. This list is not all inclusive but, rather, includes those plans that appear to cover more significant numbers of patients served by CSH.

- Aetna Health, Inc.
- AmeriChoice (Medicaid Plan of United)
- Amerigroup New Jersey*
- AmeriHealth HMO, Inc.
- Cigna
- Healthfirst Health Plan of New Jersey, Inc.*
- Horizon NJ Health*
- Oxford Health Plans
- United Healthcare
- United Community Plan*

*Medicaid Managed Care Plans Only

Other Payers reflected in CSH Payer Mix include:

- Horizon Blue Cross/Blue Shield (aka New Jersey Blue Cross Managed Care)
- New Jersey Medicaid
- Magellan
- Magellan (BC)
- Empire Blue Cross

Dominant Payers in CSH Service Locations

Bayonne (Total 213*)		
Payer	**Number**	**Percentage-Total Payers**
New Jersey Medicaid	40	18.78
AmeriChoice	32	15.20
Horizon NJ Health	38	17.84
Horizon	29	13.62

Clifton (Total 263*)		
Payer	**Number**	**Percentage-Total Payers**
New Jersey Medicaid	50	19.02
AmeriChoice	30	11.41
Horizon	26	9.89
Horizon NJ Health	24	9.13
Aetna	20	7.61
Amerigroup	14	5.32
Healthfirst	14	5.32

Fanwood (Total 128*)		
Payer	**Number**	**Percentage-Total Payers**
New Jersey Medicaid	22	17.19
Horizon	19	14.84
Horizon BC – Indiv.	14	10.94

Hamilton (Total 3,925*)		
Payer	**Number**	**Percentage-Total Payer**
New Jersey Medicaid	619	15.73
Aetna	477	12.12
Horizon	456	11.59
Horizon NJ Health	451	11.46
Horizon BC – Indiv	212	5.39
United Healthcare	185	4.70

Mountainside (total 10,196*)		
Payer	**Number**	**Percentage-Total Payers**
New Jersey Medicaid	1,514	14.85
Horizon NJ Health	1,320	12.95
AmeriChoice	1,060	10.40
Horizon	998	9.79
Aetna	989	9.70
United Healthcare	538	5.28
Cigna	467	4.58
Amerigroup	385	3.78

New Brunswick (Total 1,078*)		
Payer	**Number**	**Percentage-Total Payers**
New Jersey Medicaid	158	14.66
Horizon NJ Health	131	12.15
Horizon	107	9.93
Aetna	104	9.65
AmeriChoice	85	7.89

Roselle Park (Total 41*)		
Payer	**Number**	**Percentage-Total Payers**
Horizon NJ Health	18	43.90
AmeriChoice	10	24.39
New Jersey Medicaid	9	21.95

Toms River (Total 5,518*)		
Payer	**Number**	**Percentage-Total Payers**
New Jersey Medicaid	918	16.64
Horizon	811	14.70
Horizon NJ Health	715	12.96
AmeriChoice	569	10.31
Aetna	383	6.94
Cigna	171	3.10
United Healthcare	147	2.66
Amerigroup	113	2.05

*This number reflects the number of insured at each site of service. The Payers reflected by site only include those with the highest percentages, not all payers.

Reimbursement for Care by General Payer and by Race**

Race	Insured	Medicaid	Self Pay
White	6,783	2,759	164
Black/African American	833	1,385	23
Asian Indian	202	49	5
Multi-Racial	87	57	3
Other Races	1,211	1,690	41

**Not reflective of all races. Those with highest numbers/percentages are included. It should be noted that "Other Races" accounts for 2,942 and "Unknown" for 263. This number seems excessively large.

2011 Reimbursement for Care by General Payer Category (in millions)

Payer	Number	Percentage
Medicaid	6,151	38.6
Insurance	9,529	59.8
Self-Pay	253	1.6

2011 Children's Specialized Hospital Financial Expense

Subsidized Care $334,997

Bad Debt $2,245,184

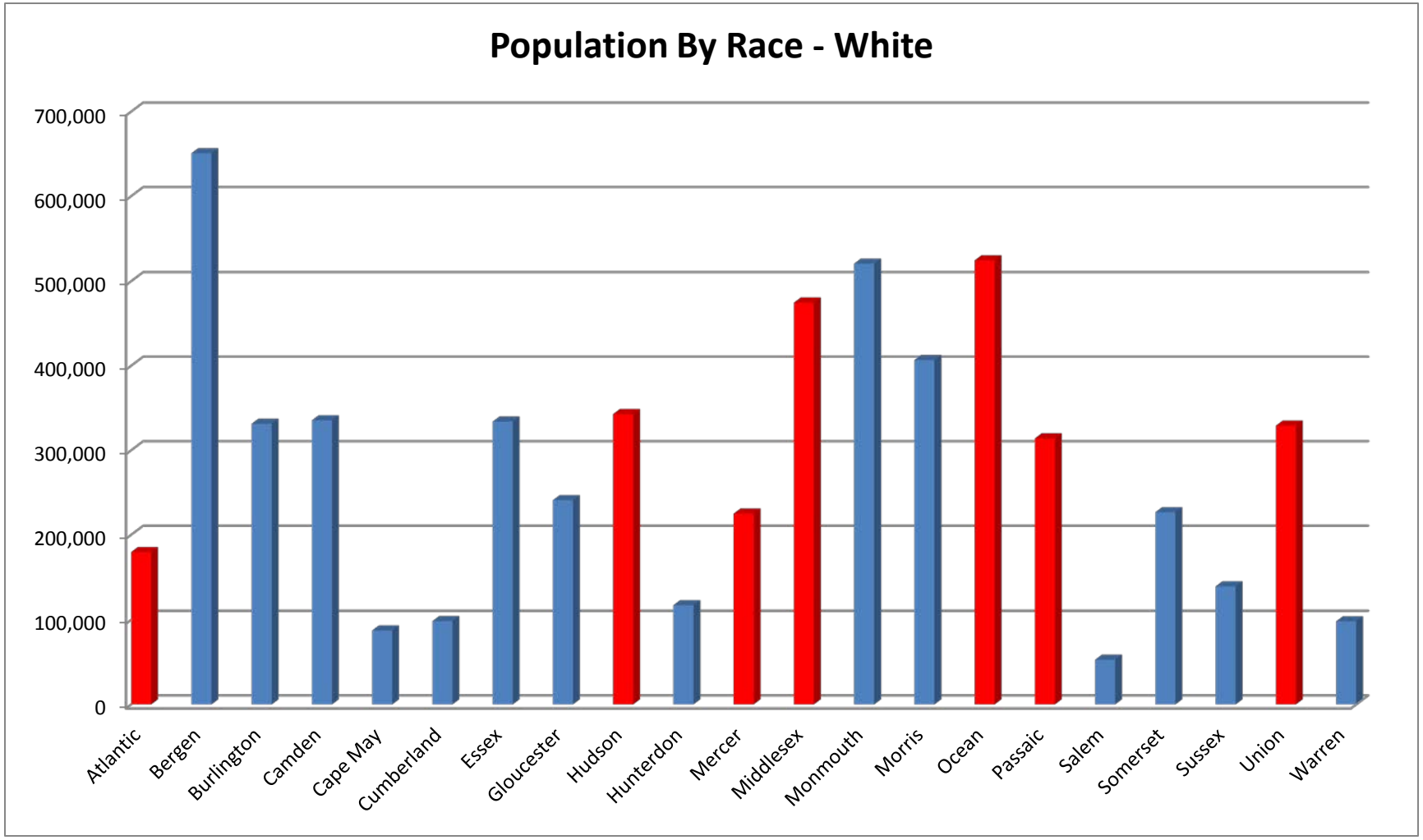
DEMOGRAPHIC DATA ANALYSIS

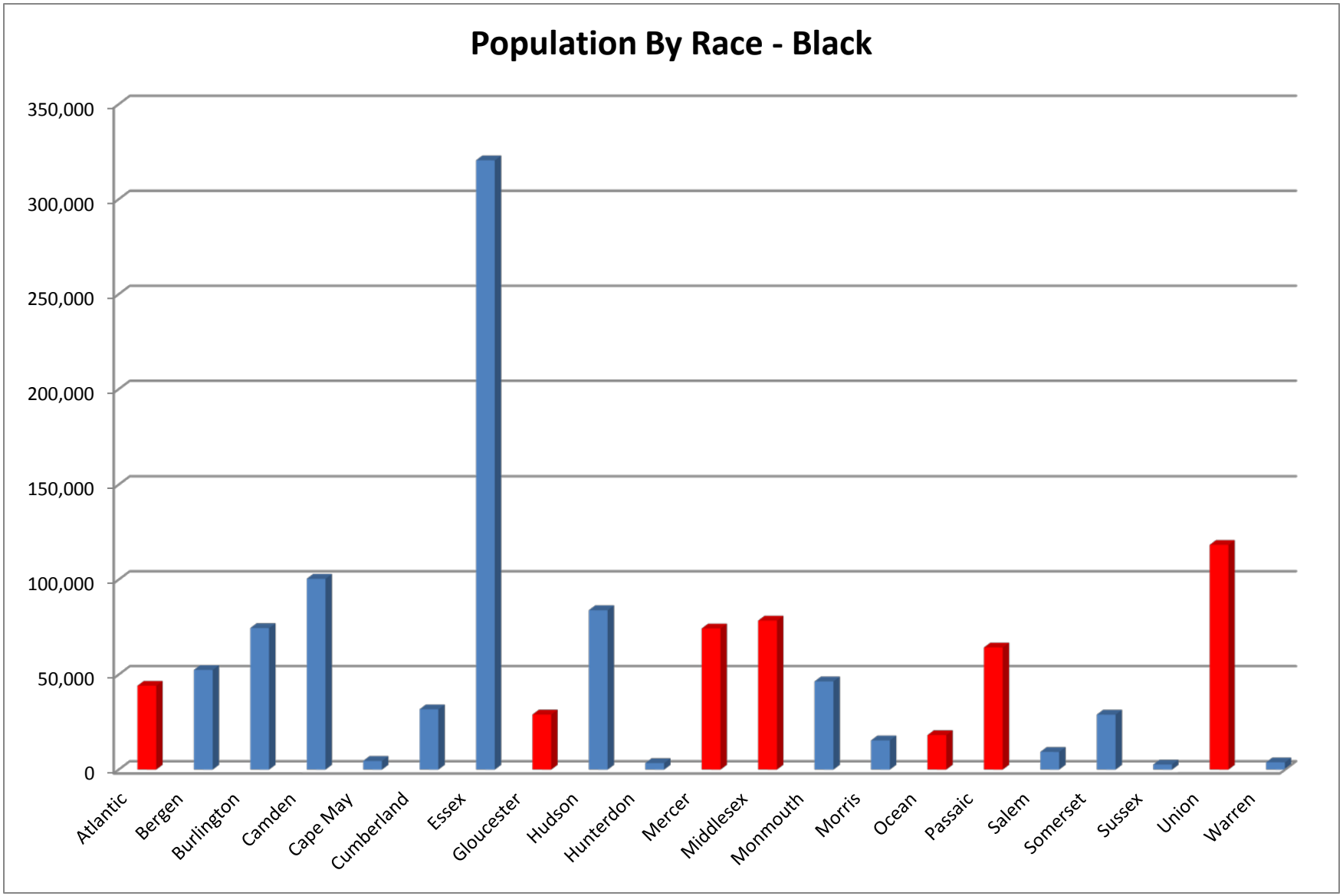
The following graphs provide a number of demographic indicators that can be used in analyzing access, utilization and finances. More specifically, when examining charts related to race and income, these figures can be reviewed in light of the current population served by CSH. For example, if there are counties with a relatively high number of children with disabilities, then a zip code analysis can be conducted by CSH to determine if they are drawing children from these areas and, if not, how they are receiving services. A more in-depth analysis can be conducted. These graphs should provide a picture of what communities within counties look like and allow CSH to determine if there may be unmet needs. Often more detailed analysis at zip code levels as well as additional focus groups or surveys allow one to drill down to determine if there are barriers to accessing care, i.e., transportation, financial resources, lack of awareness or people just feeling alienated from the healthcare system in general.

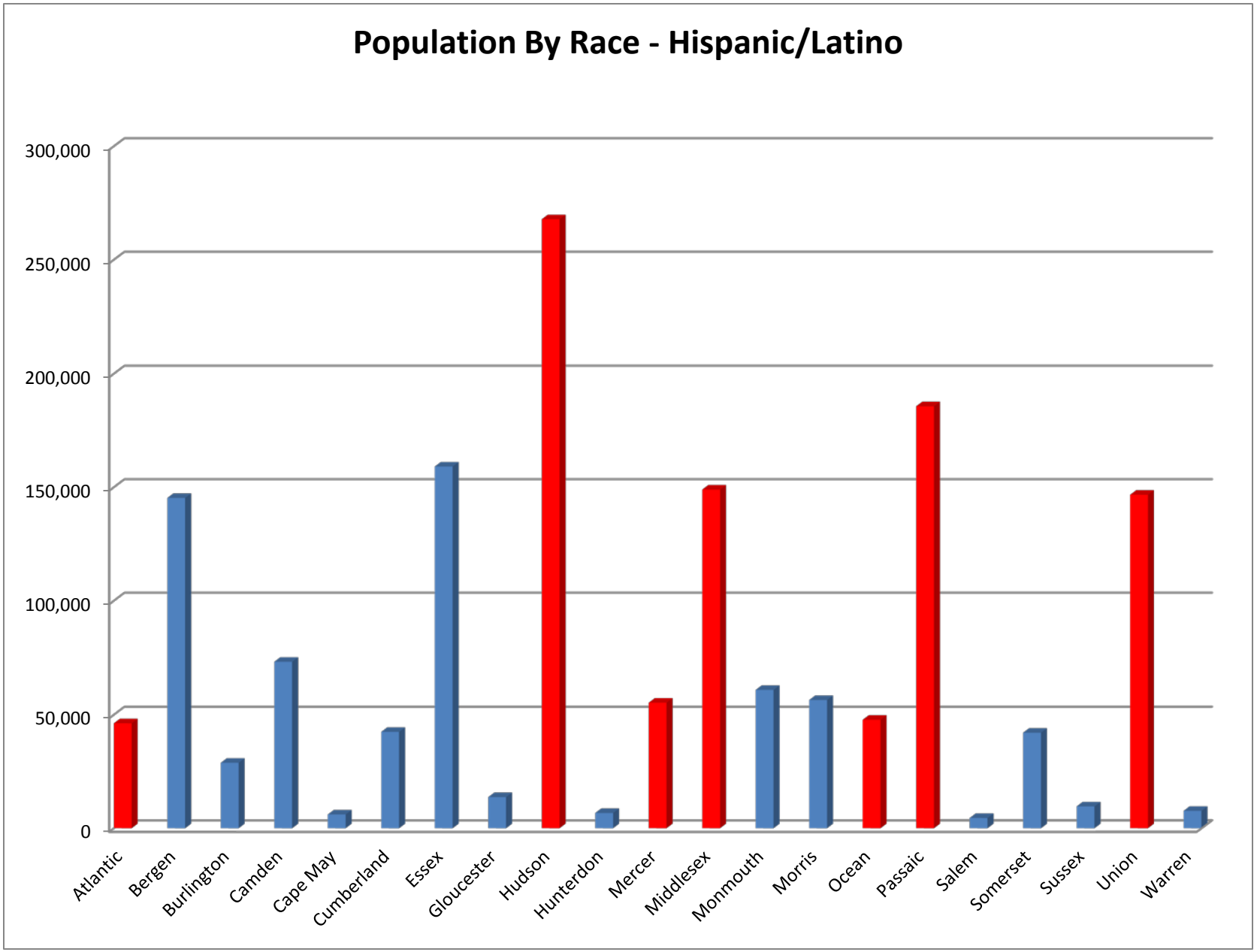
The graphs present a broad picture of all of the counties within New Jersey. This is necessary as CSH does not have a "defined" community but rather serves children throughout the state, therefore, an analysis cannot be limited to just the counties in which CSH offers services.

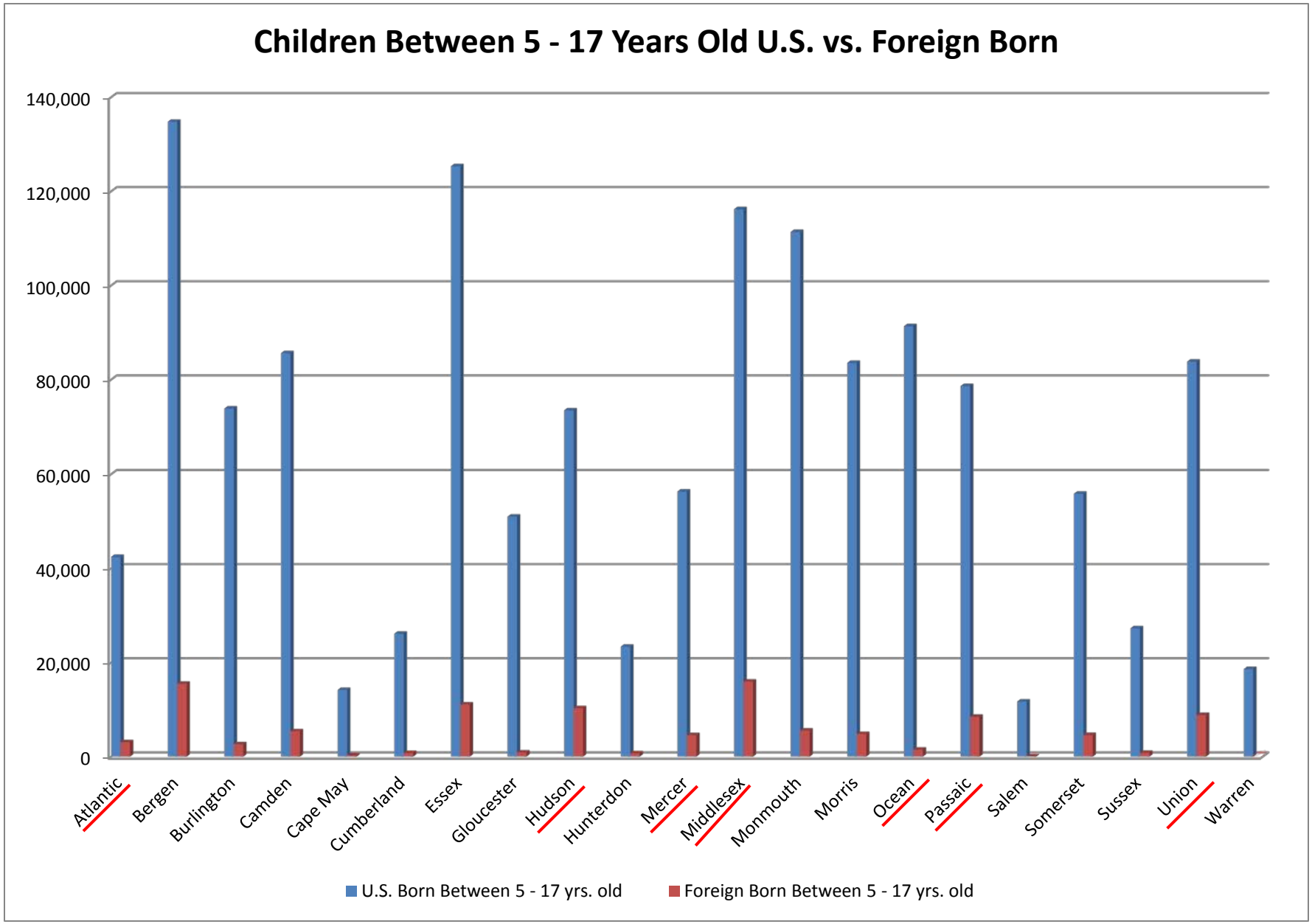
POPULATION BY RACE

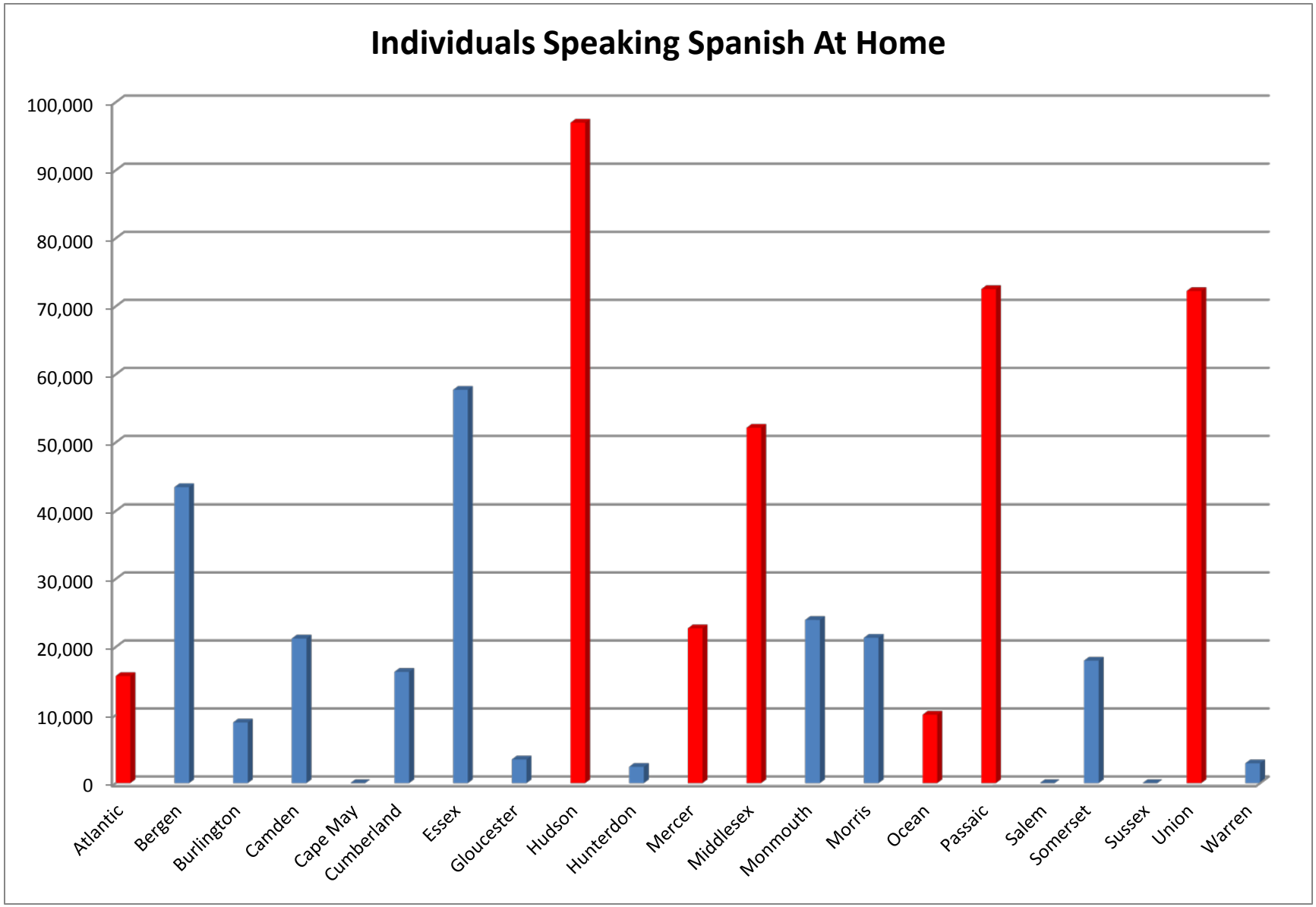
Single Data Element Bar Graphs – Red Columns indicate counties where CSH has a site.
Multiple Data Element Bar Graphs – Counties underlined in red indicate CSH site.

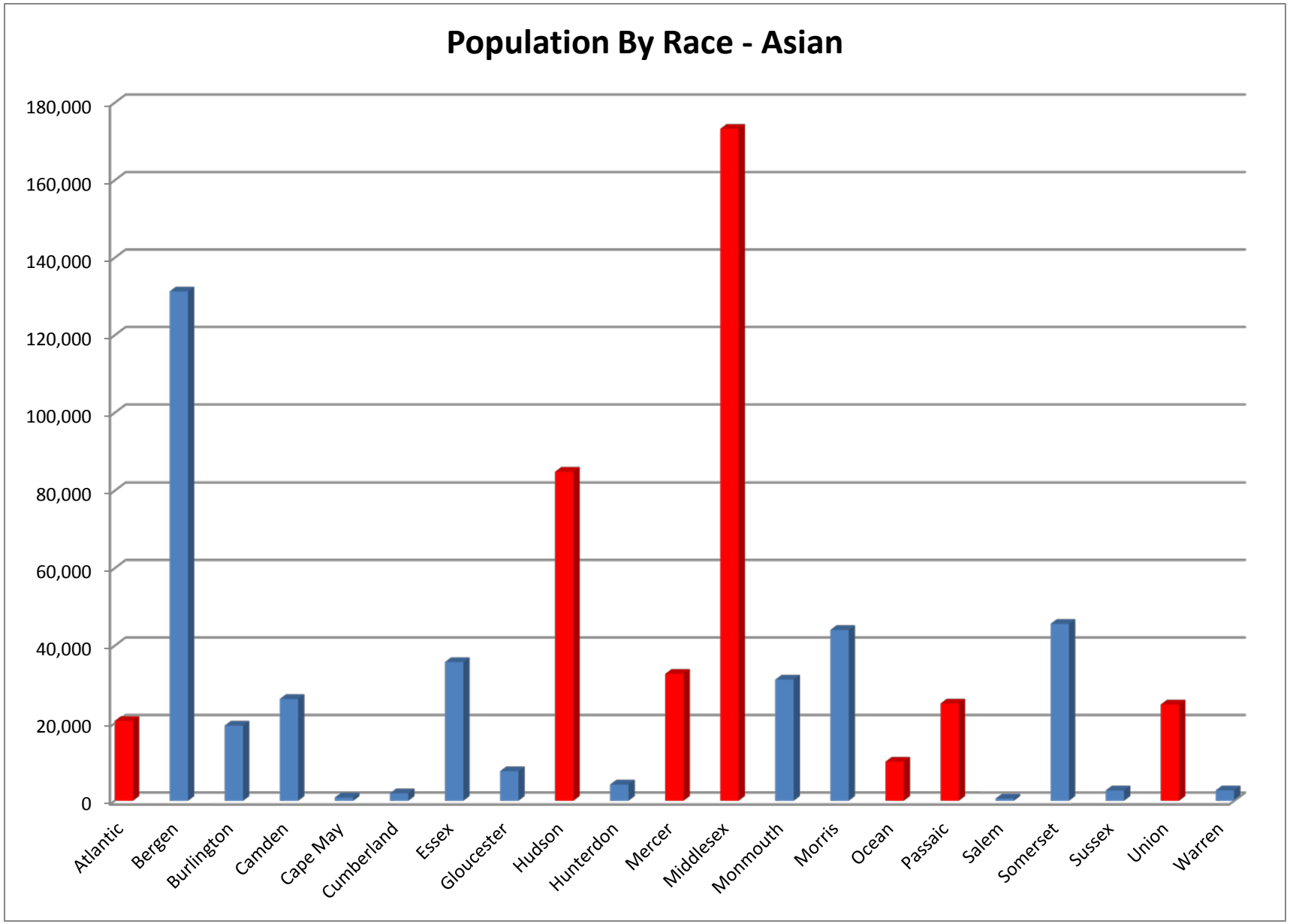

Population By Race - White
700,000
600,000
500,000
400,000
300,000
200,000
100,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

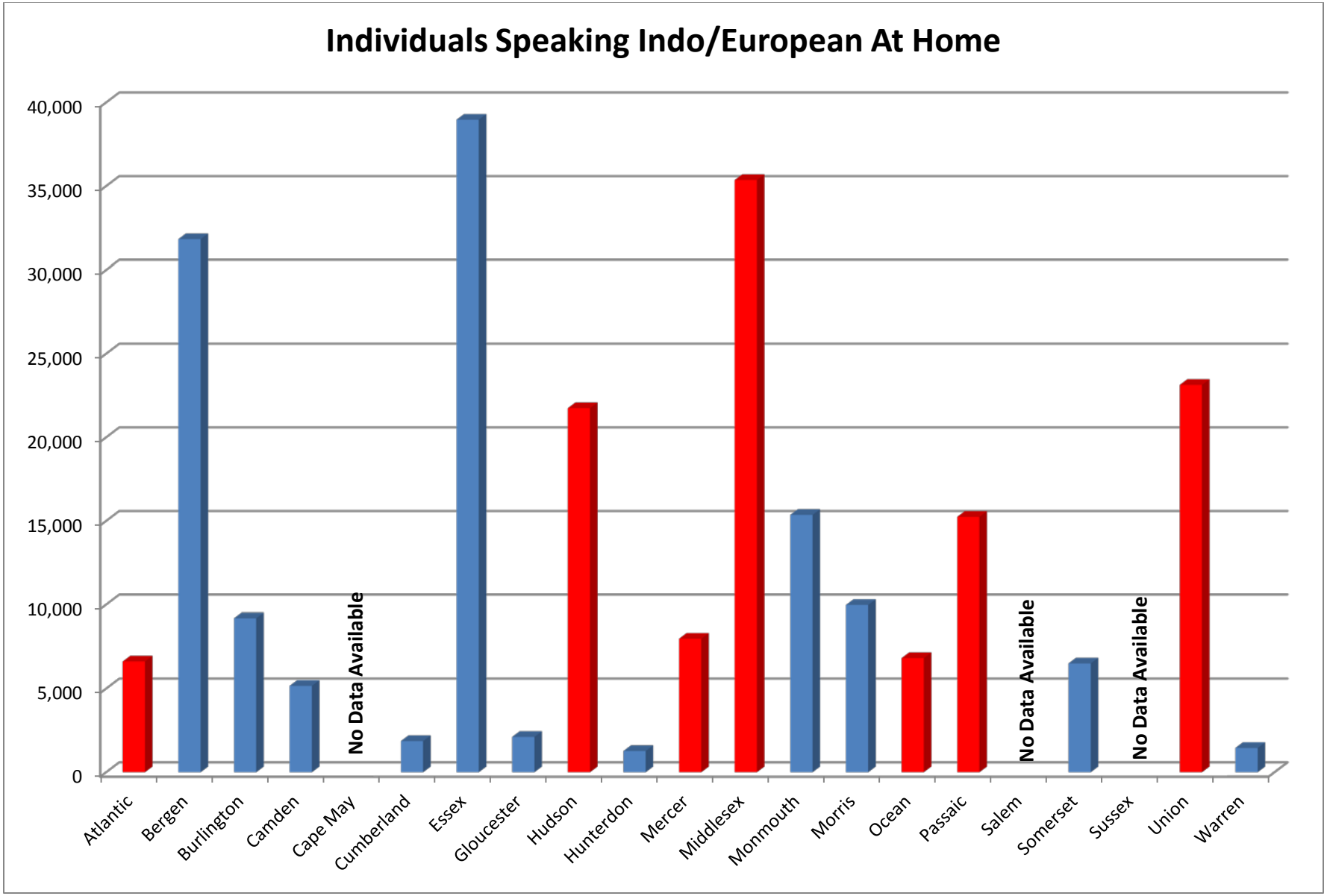

Population By Race - Black
350,000
300,000
250,000
200,000
150,000
100,000
50,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

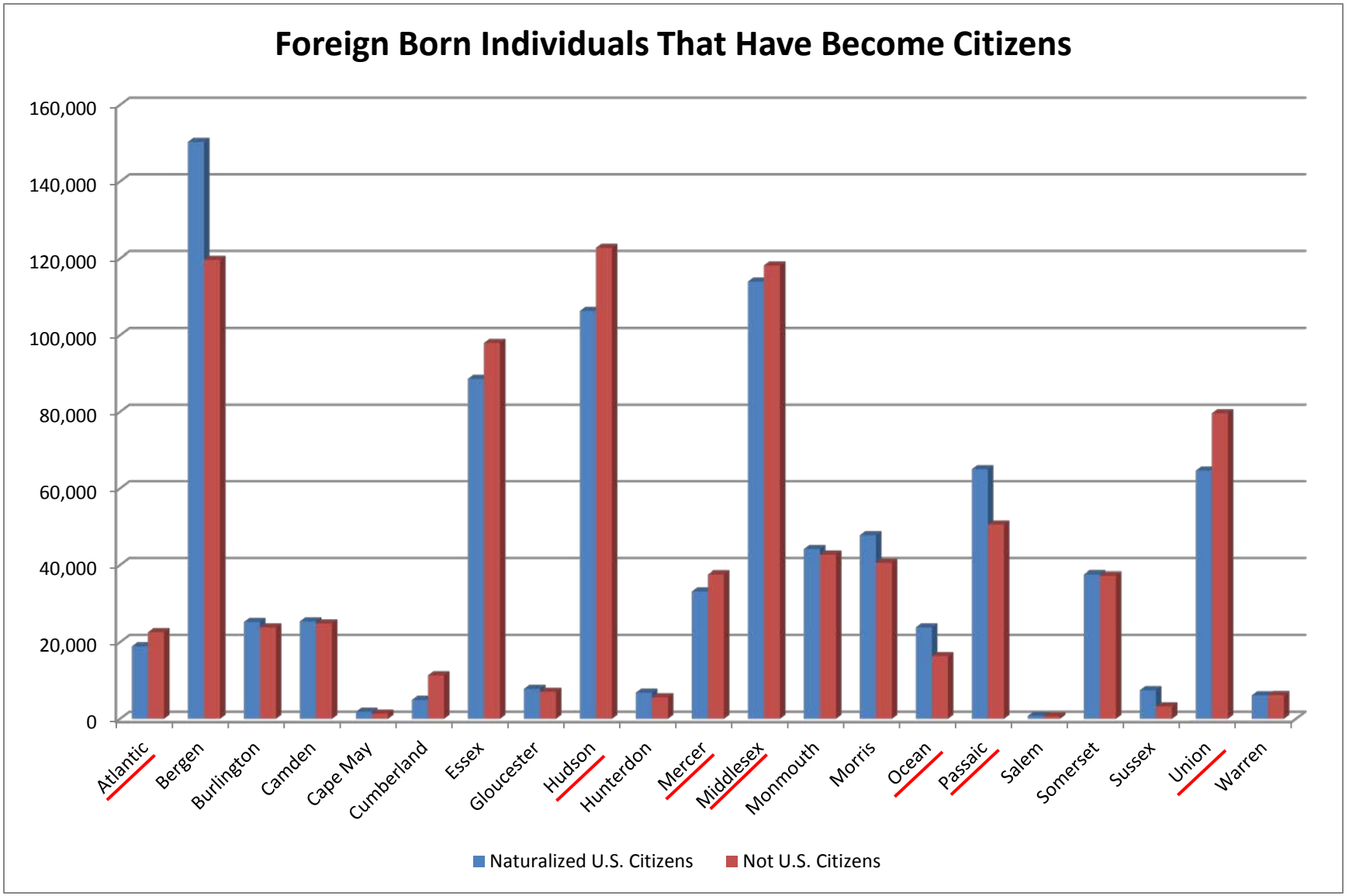

Population By Race - Hispanic/Latino
300,000
250,000
200,000
150,000
100,000
50,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren


Children Between 5 - 17 Years Old U.S. vs. Foreign Born
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren
U.S. Born Between 5 - 17 yrs. old
Foreign Born Between 5 - 17 yrs. old


Individuals Speaking Spanish At Home
100,000
90,000
80,000
70,000
60,000
50,000
40,000
30,000
20,000
10,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

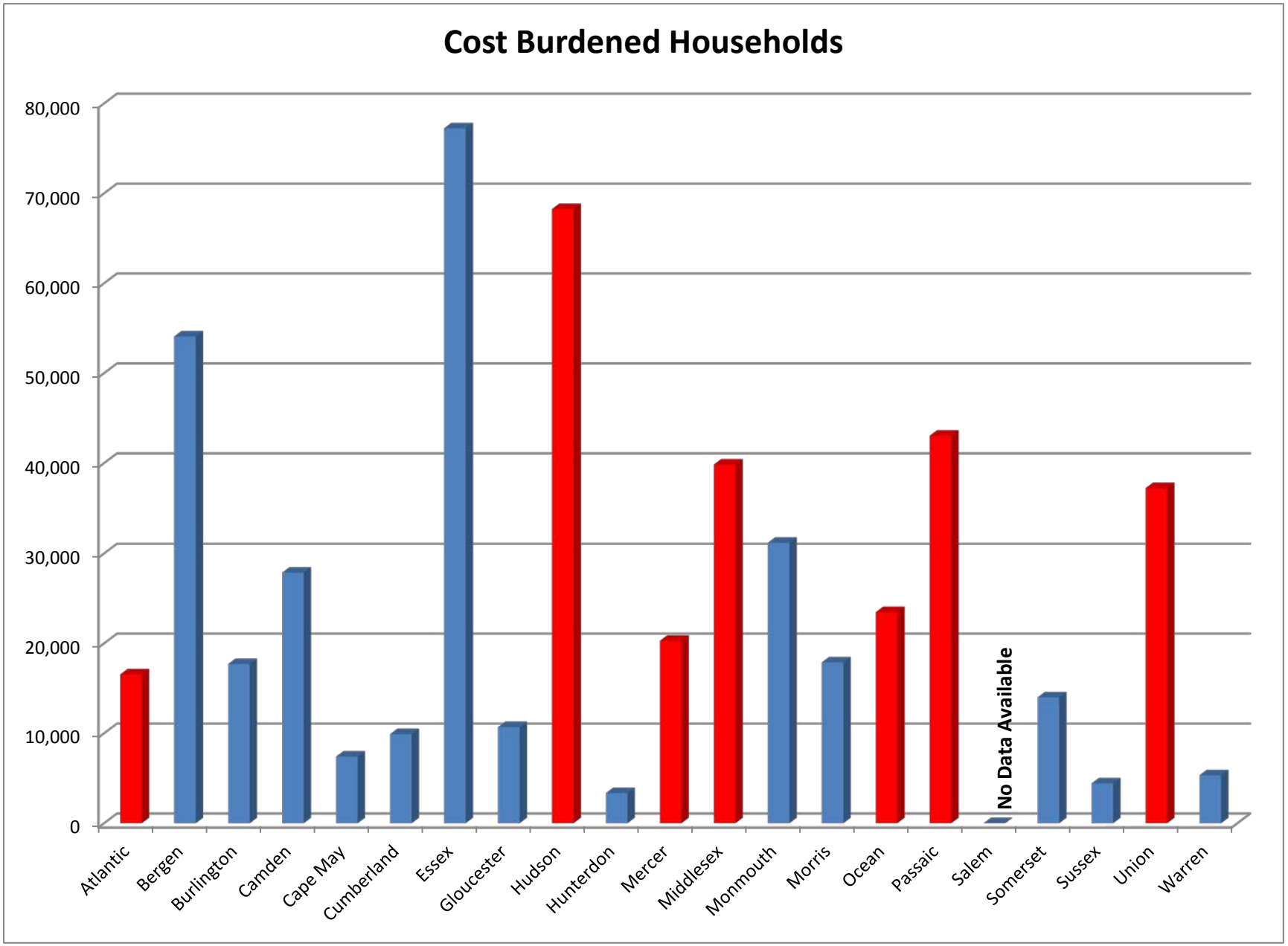

Population By Race - Asian
180,000
160,000
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

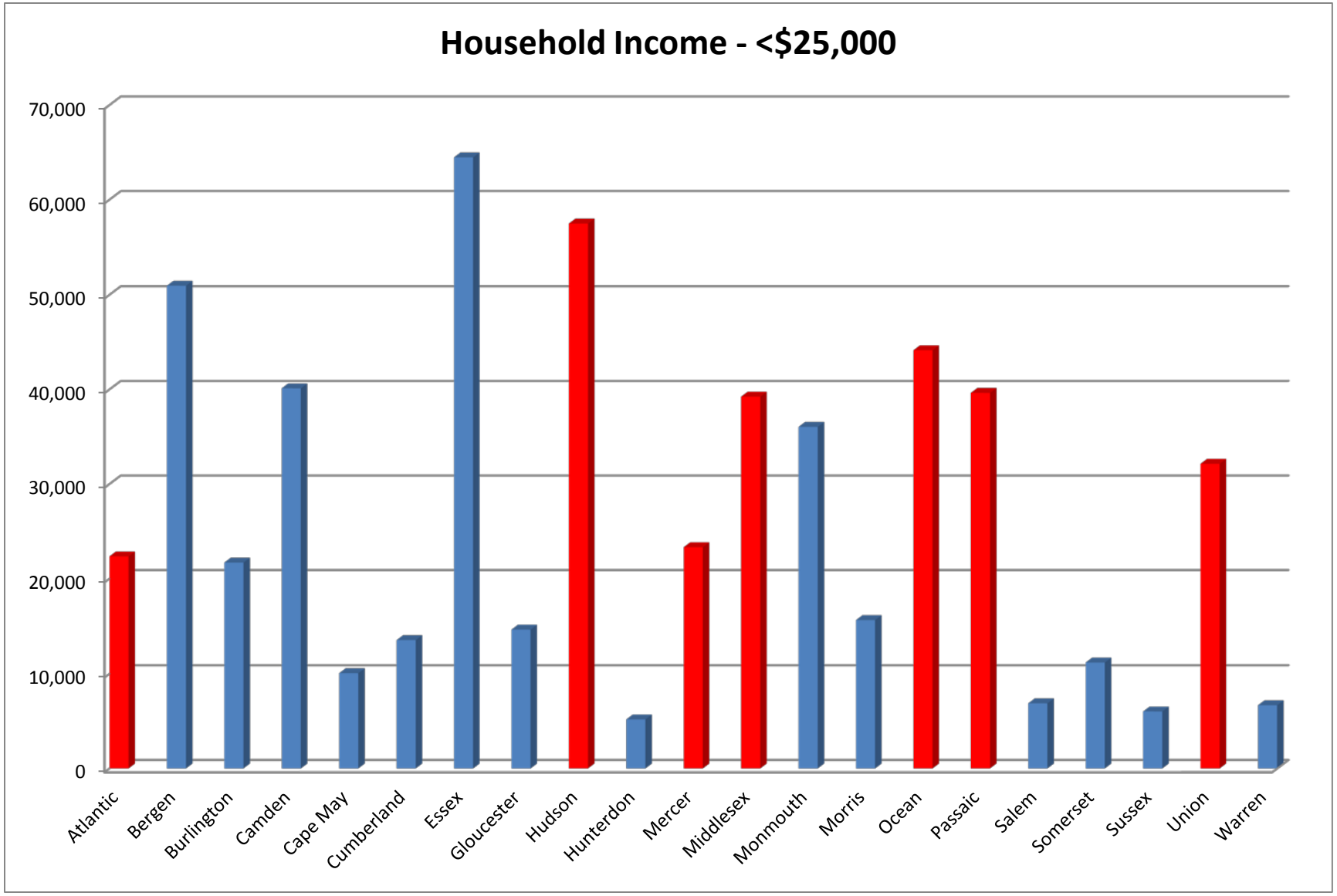

Individuals Speaking Indo/European At Home
40,000
35,000
30,000
25,000
20,000
15,000
10,000
5,000
0
No Data Available
No Data Available
No Data Available
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

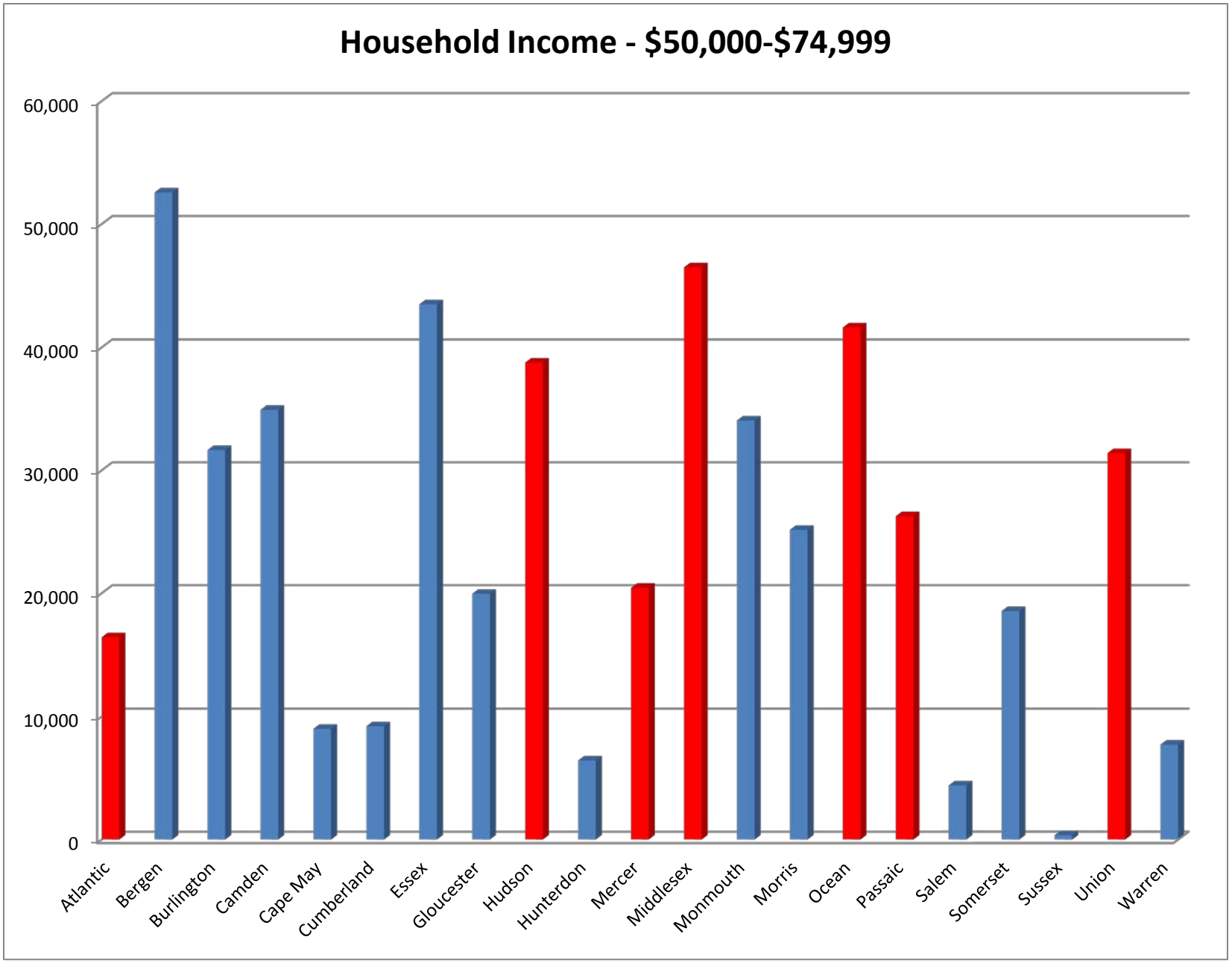

Foreign Born Individuals That Have Become Citizens
160,000
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren
Naturalized U.S. Citizens
Not U.S. Citizens

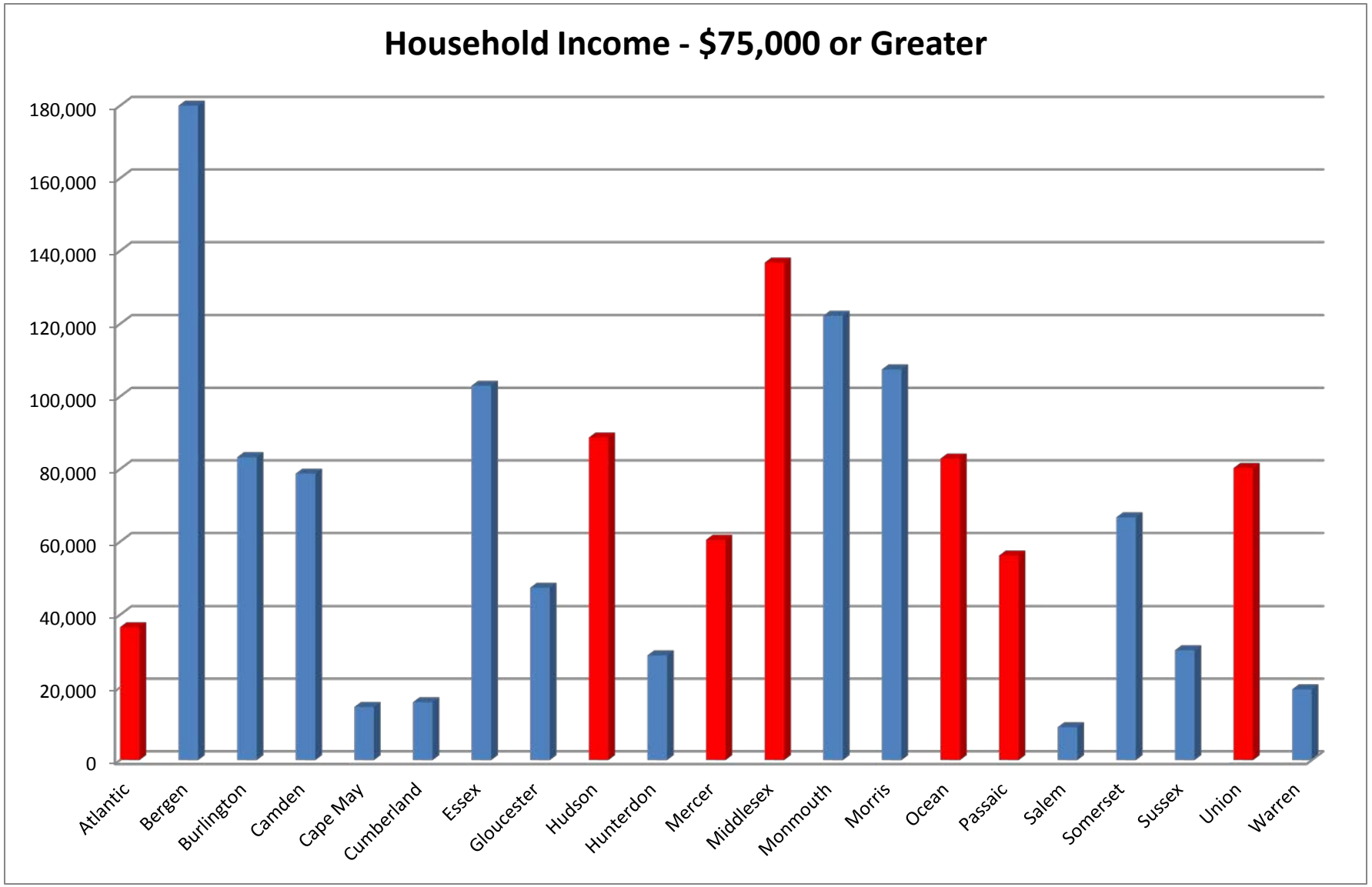
HOUSEHOLD INCOME

Single Data Element Bar Graphs – Red Columns indicate counties where CSH has a site.
Multiple Data Element Bar Graphs – Counties underlined in red indicate CSH site.


Cost Burdened Households
80,000
70,000
60,000
50,000
40,000
30,000
20,000
10,000
0
No Data Available
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

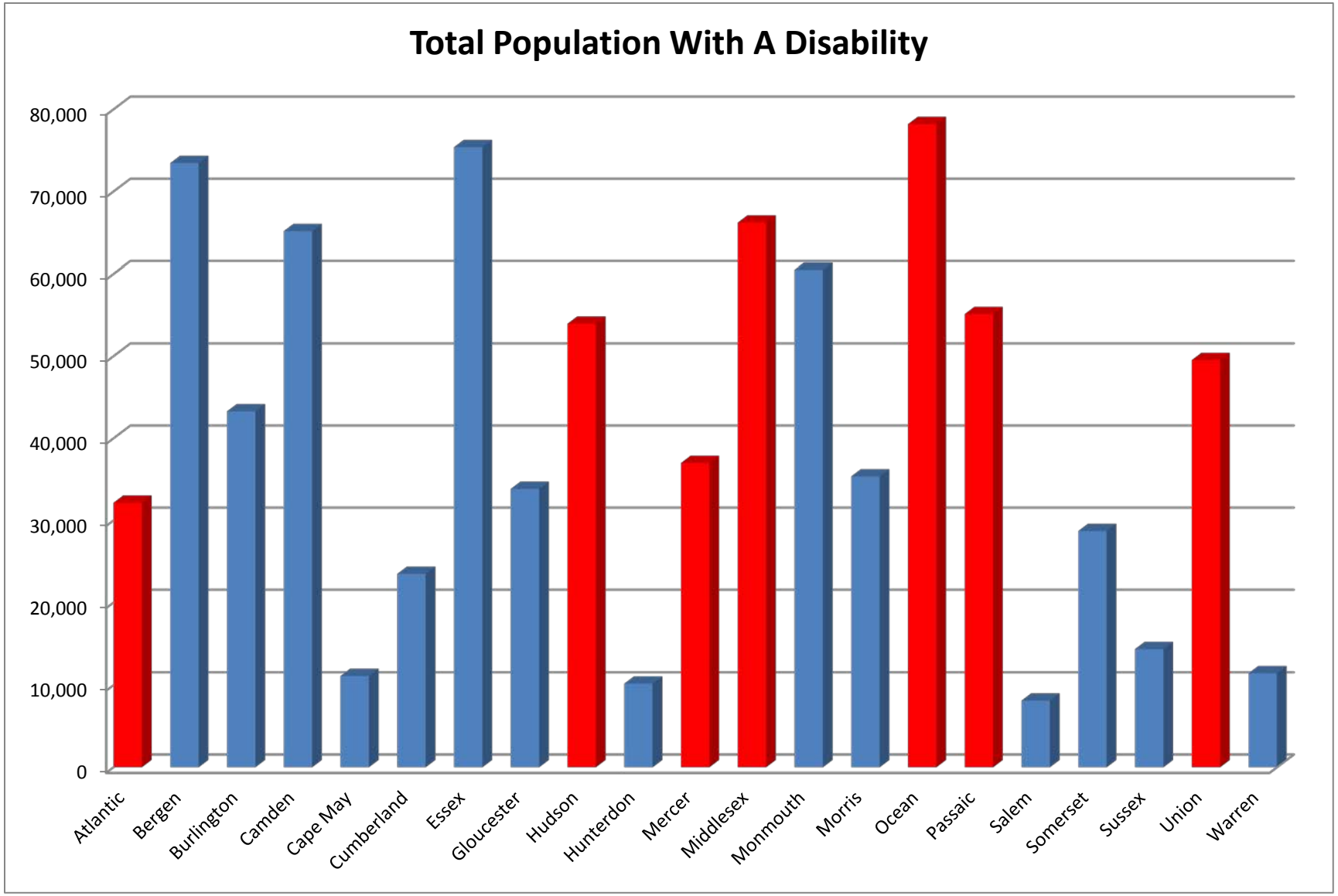

Household Income - <$25,000
70,000
60,000
50,000
40,000
30,000
20,000
10,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

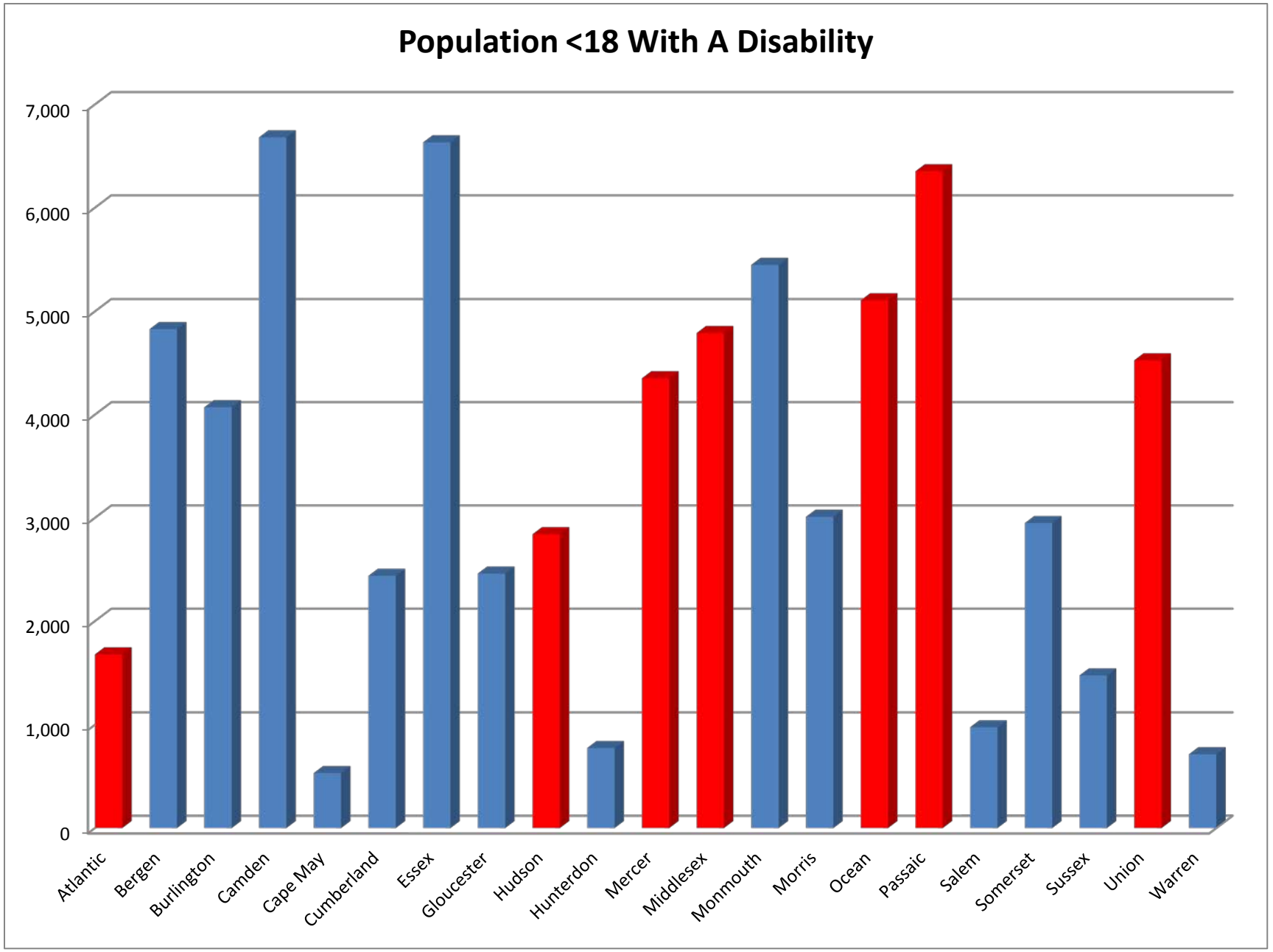

Household Income - $50,000-$74,999
60,000
50,000
40,000
30,000
20,000
10,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

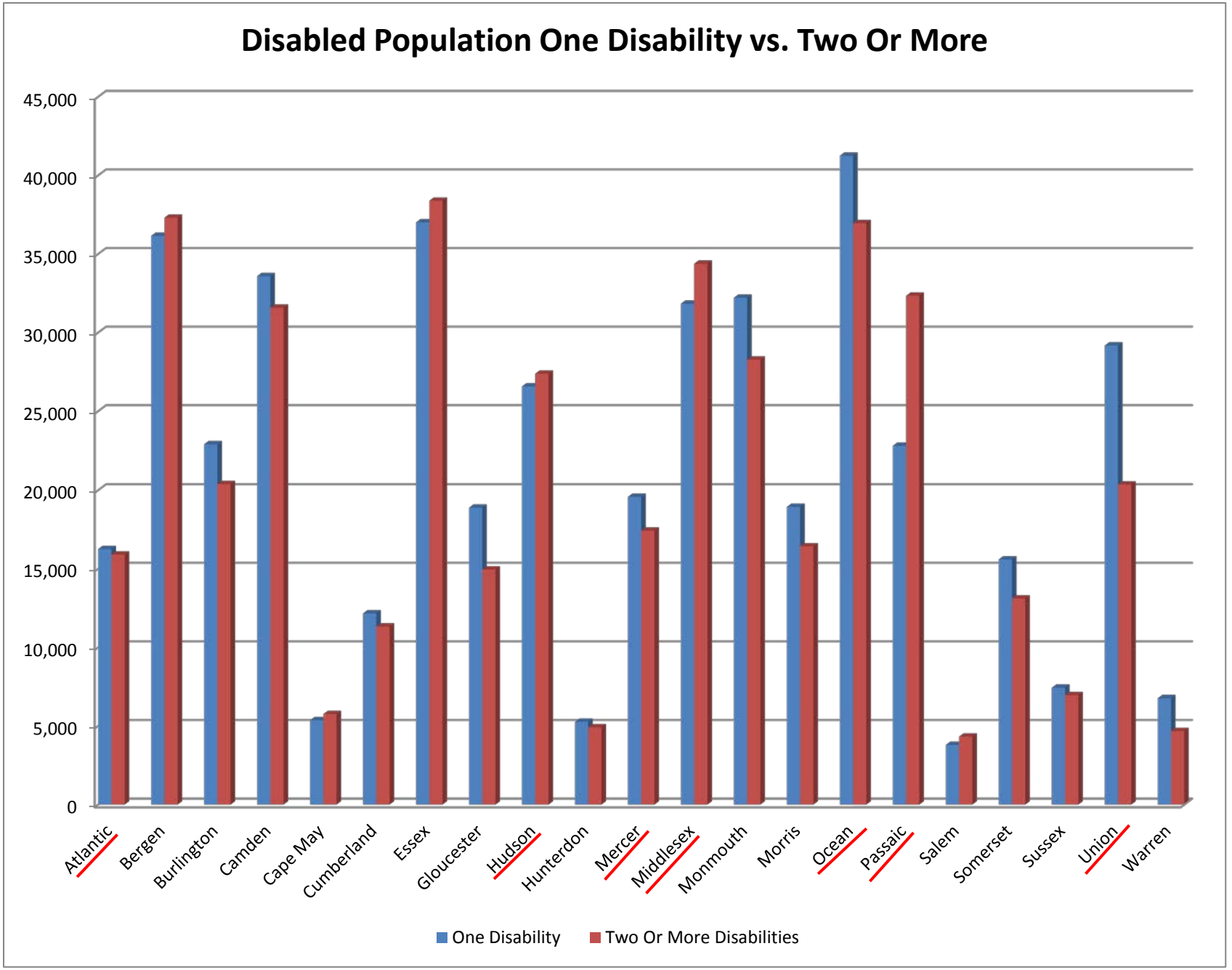

Household Income - $75,000 or Greater
180,000
160,000
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

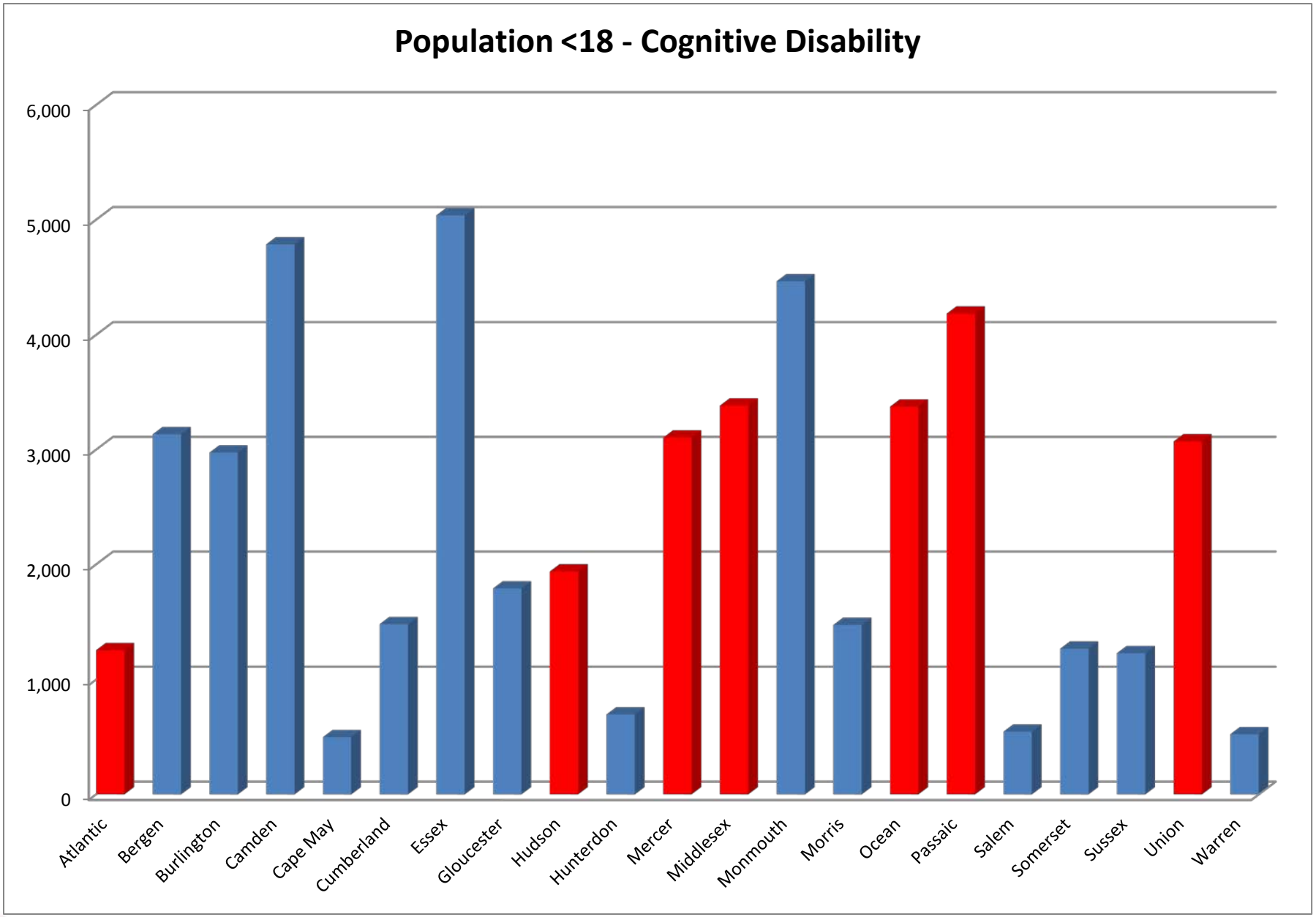
DISABILITIES

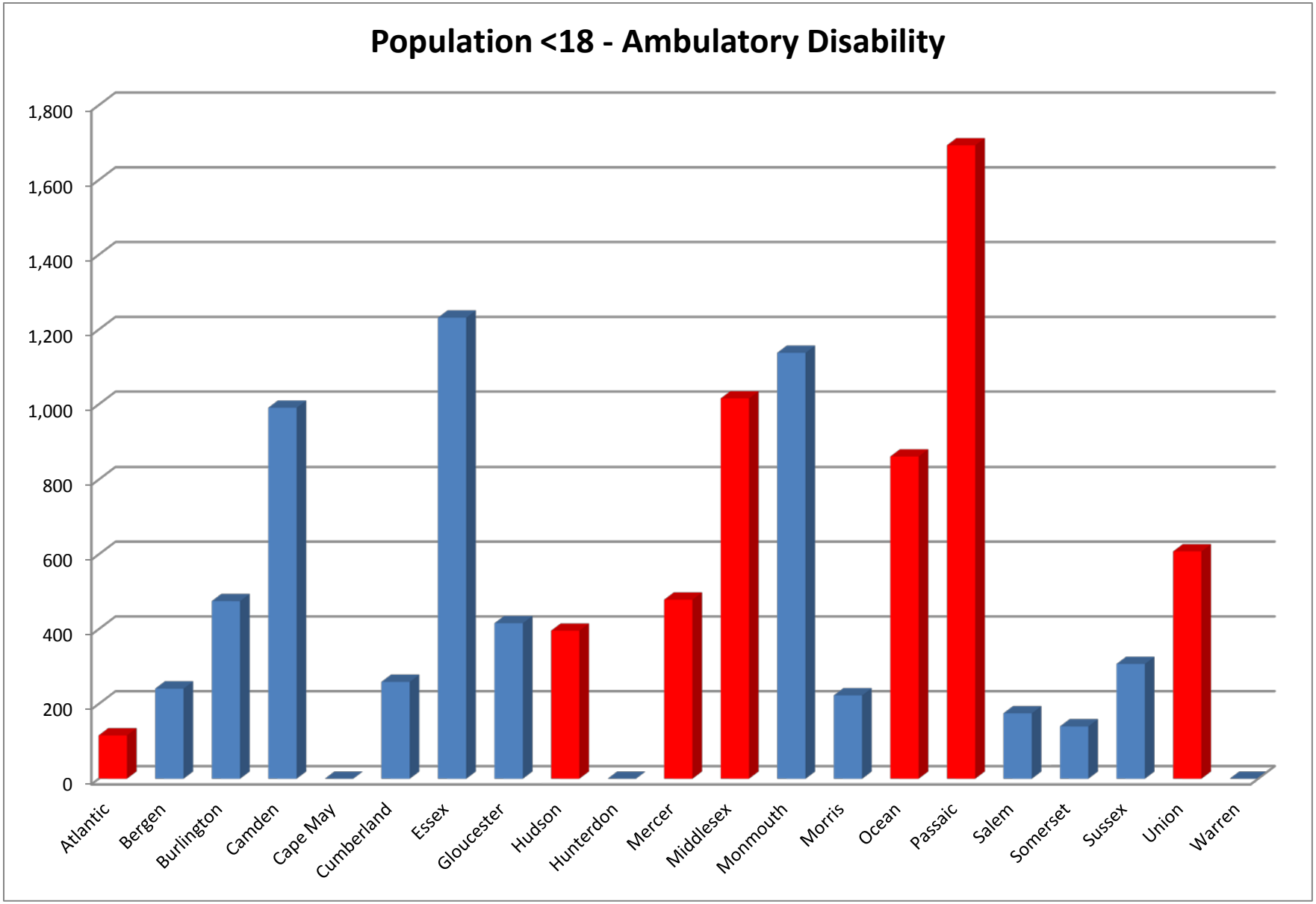
Single Data Element Bar Graphs – Red Columns indicate counties where CSH has a site.
Multiple Data Element Bar Graphs – Counties underlined in red indicate CSH site.

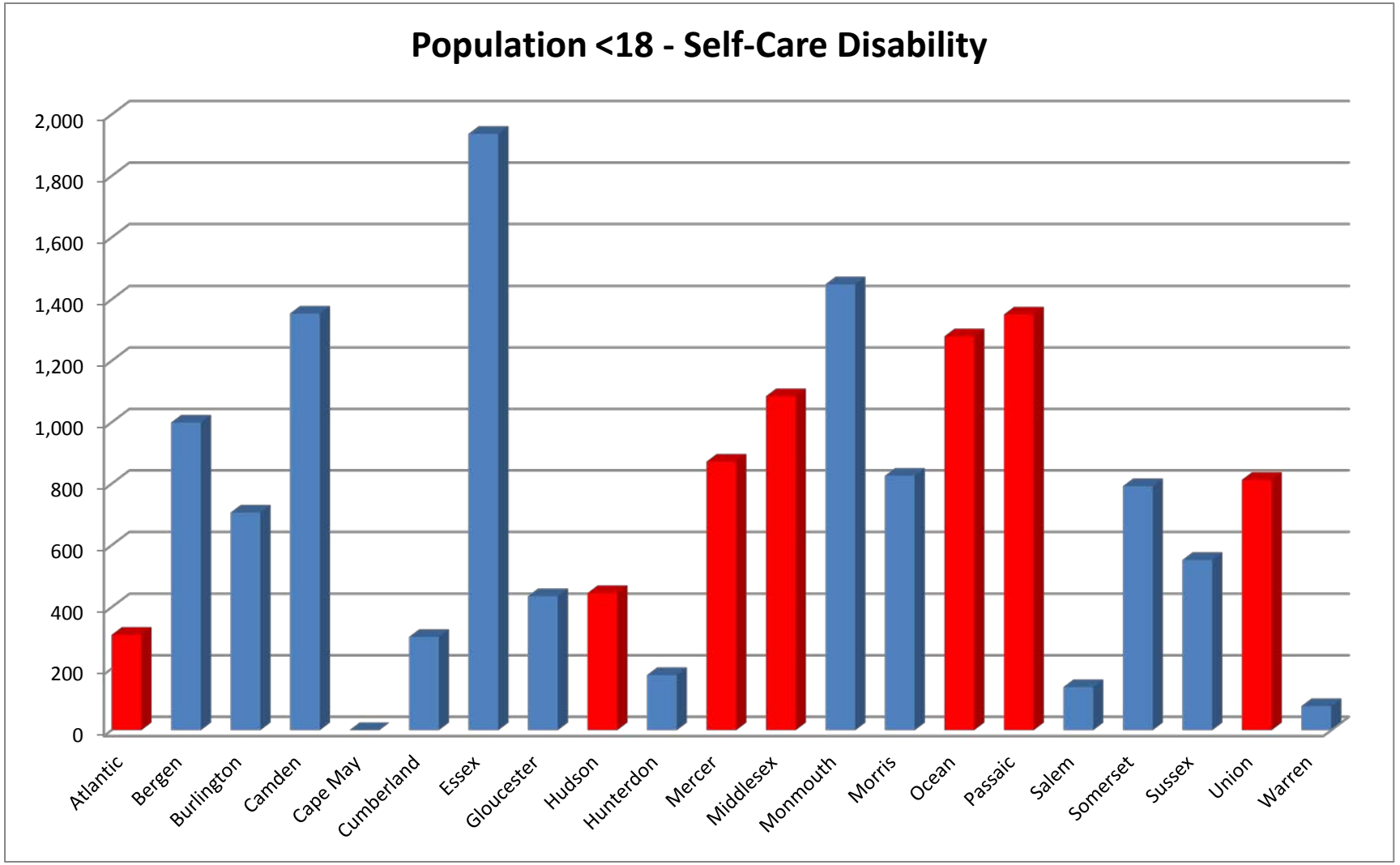

Total Population With A Disability
80,000
70,000
60,000
50,000
40,000
30,000
20,000
10,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

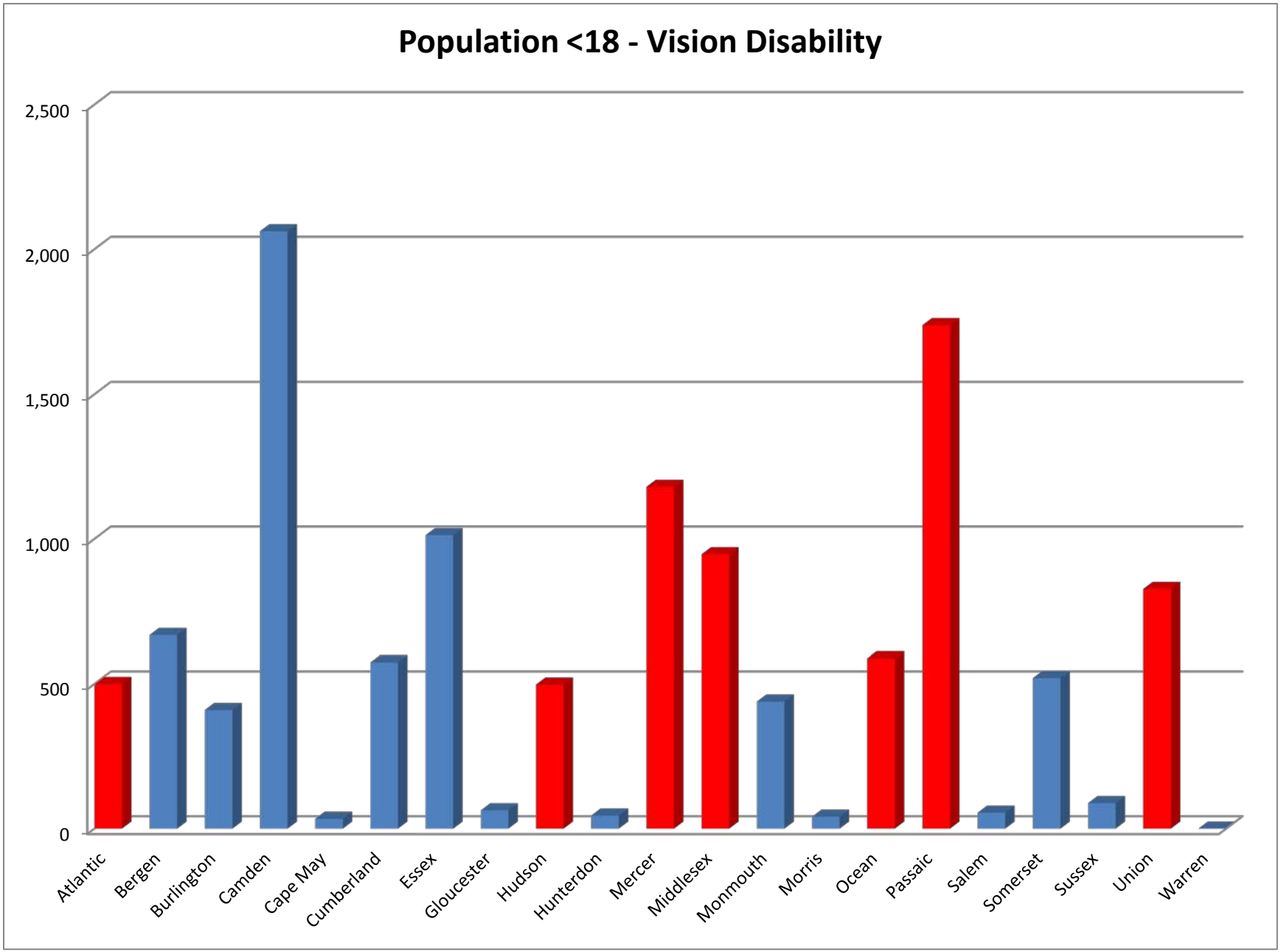

Population <18 With A Disability
7,000
6,000
5,000
4,000
3,000
2,000
1,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

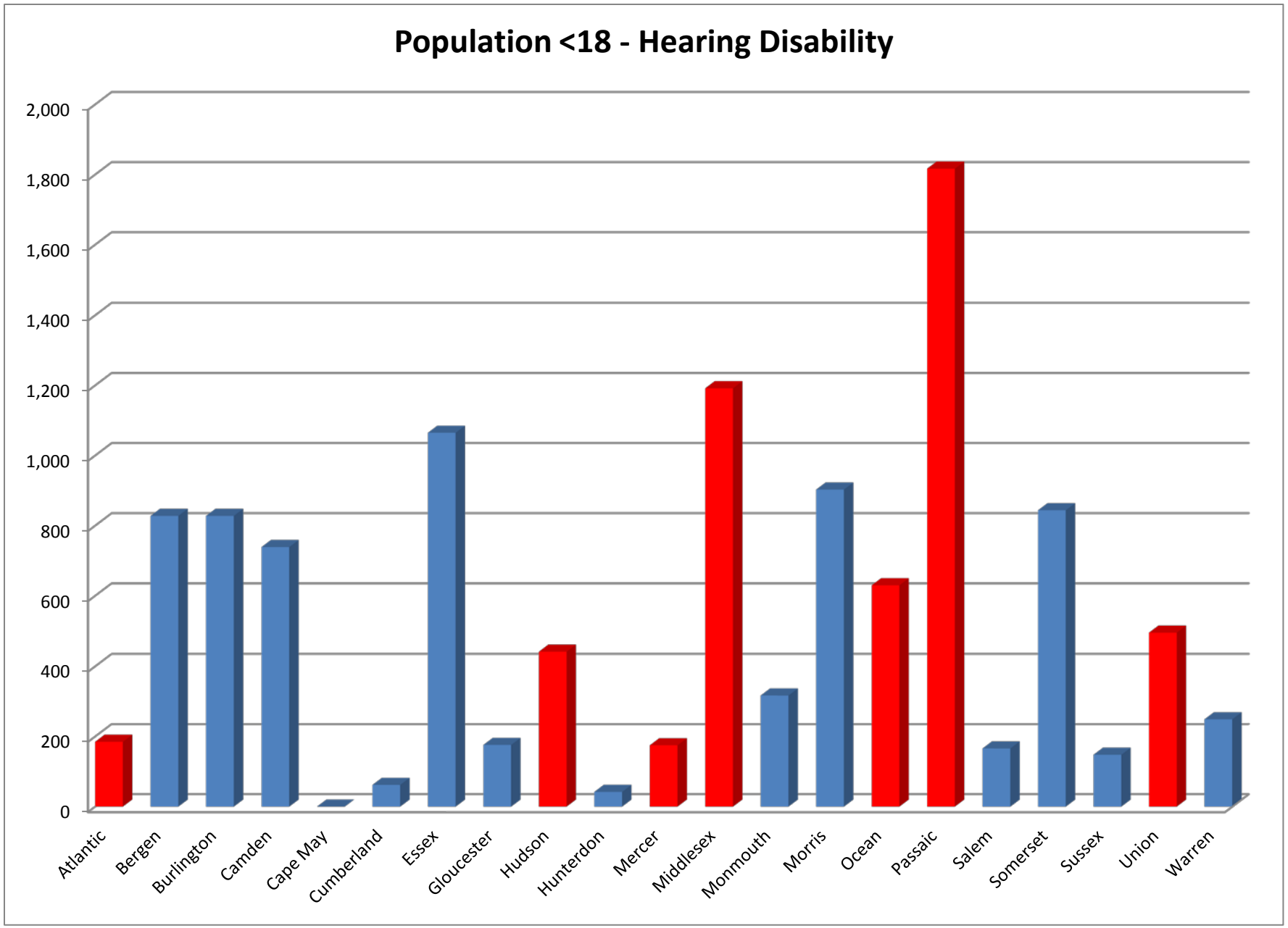

Disabled Population One Disability vs. Two Or More
45,000
40,000
35,000
30,000
25,000
20,000
15,000
10,000
5,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren
One Disability
Two Or More Disabilities


Population <18 - Cognitive Disability
6,000
5,000
4,000
3,000
2,000
1,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren


Population <18 - Ambulatory Disability
1,800
1,600
1,400
1,200
1,000
800
600
400
200
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

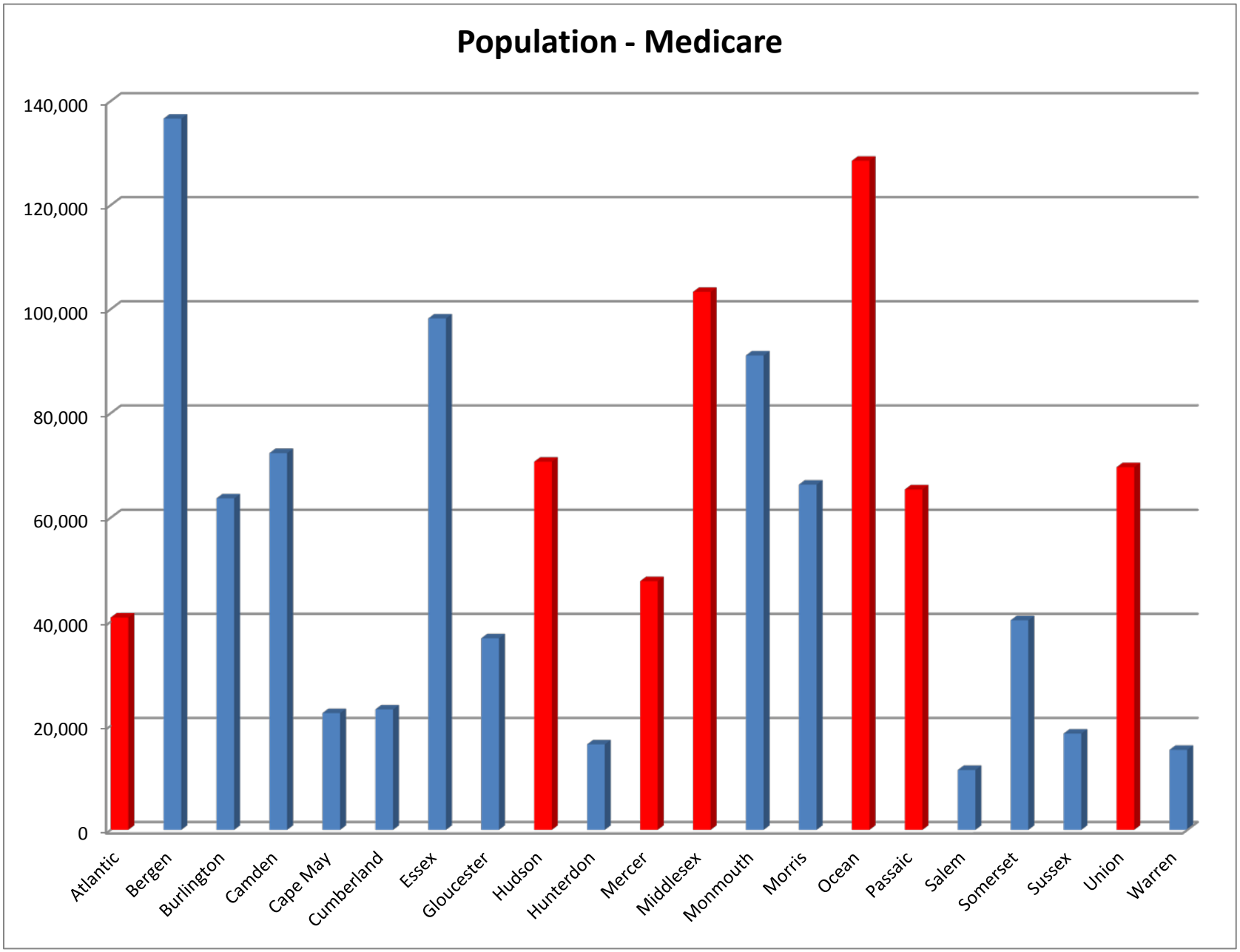

Population <18 - Self-Care Disability
2,000
1,800
1,600
1,400
1,200
1,000
800
600
400
200
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

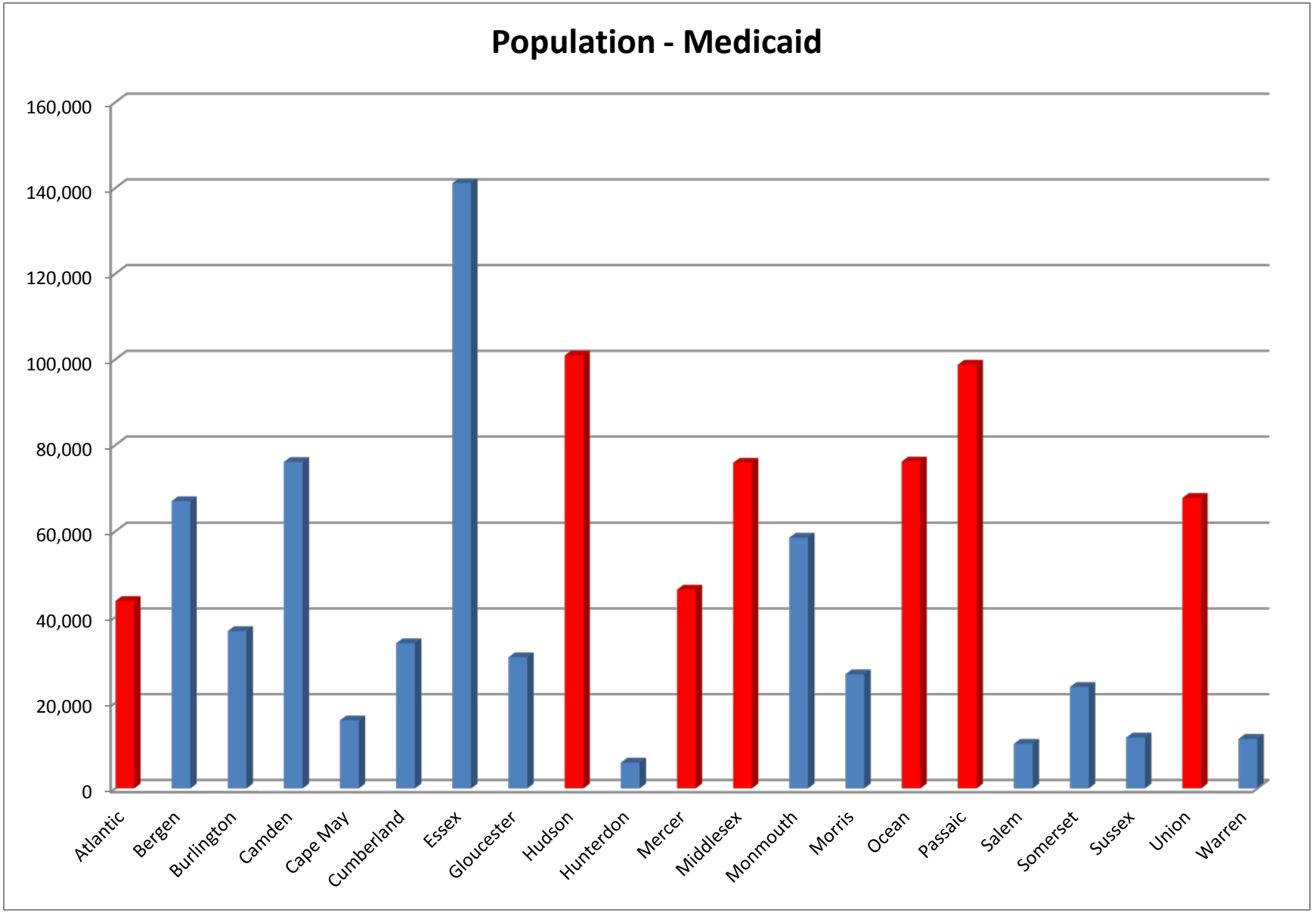

Population <18 - Vision Disability
2,500
2,000
1,500
1,000
500
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren


Population <18 - Hearing Disability
2,000
1,800
1,600
1,400
1,200
1,000
800
600
400
200
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren

INSURANCE

Single Data Element Bar Graphs – Red Columns indicate counties where CSH has a site.
Multiple Data Element Bar Graphs – Counties underlined in red indicate CSH site.


Population - Medicare
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
Ocean
Passaic
Salem
Somerset
Sussex
Union
Warren


Population - Medicaid
160,000
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
Atlantic
Bergen
Burlington
Camden
Cape May
Cumberland
Essex
Gloucester
Hudson
Hunterdon
Mercer
Middlesex
Monmouth
Morris
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Somerset
Sussex
Union
Warren

Key Informant Interviews

CSH's Senior Leadership Team was asked to provide names of individuals they believed would offer a valuable perspective of both external forces and points of view that have or could impact and guide CSH. In addition, some CSH staff as well as a Trustee were interviewed as they had a history with CSH and an in-depth knowledge of the services and programs offered by CSH on both an inpatient and outpatient basis (See Appendix F for complete interview responses).

Questions were developed to meet the following objectives:

- Determine the type of interaction with CSH;
- Determine if there have been changes in demographics as they relate to children with special needs;
- Identify changes in relation to the types of services needed by children with special needs;
- Identify the challenges in covering the cost associated with children with special needs;
- Provide ideas about what could be done differently, if anything, with the relationship among the providers and parents; and
- Determine if there are sufficient services and/or sites of services to meet the children's' special needs.

Interviews were conducted via telephone by the project director and lasted, on average, 30 – 45 minutes. Key informants were notified in advance of the interview to enlist their participation. An interview guide was used to facilitate discussion (Appendices A and B). Key questions were developed but modified based on the organization and/or position held by the person being interviewed.

Questions included the following:

- What is your role within your organization?
- How do you interact with CSH?
- What changes have you seen with CSH over the years?
- Have you seen a change in the demographics as they relate to children with special needs?
- Have there been changes in relation to the types of services needed by children with special needs?
- What could be done differently, if anything, with the relationship among the providers, health plans and parents?
- Are there sufficient resources to meet the children's' special needs?
- Are there barriers that prevent or create obstacles to CSH's future growth?
- What could be done to overcome these challenges?
- What changes do you believe could/should be made to continue to improve upon CSH services?

Key Informants represented:

Amerigroup Health Plan
The CSH Foundation
The Board of Trustees – Foundation Board
CSH Outpatient Services

There was general consensus among Informants that there were some changes that have occurred over the years that have significantly impacted CSH. In addition, there were areas where CSH could improve.

Responses include (complete responses are included in Appendix F):

- There has been tremendous growth with facilities and services within the past several years and this growth can be attributed in large part to the leadership of CSH.

  "There has been significant growth in facilities and services. Instead of treating 2,000 – 4,000 kids a year, CSH is treating 20,000 a year."

  "Expansion continues to broaden the reach of the hospital and seems to be driving the needs of the population base."

- Financial support for care continues to be a challenge attributed in large part to changes in reimbursement and an increasing number of children requiring financial assistance. Foundation fundraising must keep pace with this expansion and continued need for funds.

  "There has been a shift of services into managed care. For example, Medical Day Care is now managed by the health plans rather than directly from the State. Long-term care will also shift to managed care. When the State cuts the rates it pays health plans, the plans (some plans but eventually may be all plans) will cut reimbursement to providers."

  "Medicaid reimbursement is grossly inadequate as the rates are based on long-term care. These rates do not take into account the complexity of the diagnoses and level of care patients/children require."

- There needs to be greater visibility and education regarding the services and programs offered by CSH.

  "Pre-conceived ideas about CSH and its services need to be addressed. For example, parents of children with orthopedic injuries would not necessarily know that they could receive treatment at CSH. The common response from parents is "Oh my gosh, I didn't know you did this."

- *Providers do have an awareness of CSH **if** they have referred children in the past; however, educators are less familiar with CSH and its services.*

- *Educators tend to be wary that if they refer a child to CSH parents will think the school should provide the recommended services and there should be no cost to the parents. This creates challenges for a school as school districts have experienced significant funding cuts.*

Additional issues as well as suggestions regarding what should be done to improve upon CSH's services and programs varied based on the position/organization of the Informant. It was suggested that:

- Communication between the health plans and certain providers such as those in medical day care and home health care should ensure children are getting certain services such as vaccines, well-visits, etc. Plans are held to specific state benchmarks and working with providers will help ensure children are receiving appropriate services and the health plans are performing in relation to expectations of the State.

- Issues related to mental health must be addressed; more specifically, the existing mental health network is crisis-oriented, not preventive. Moreover, the network of professionals that will participate in managed care plans is scarce.

- CSH's Foundation must keep pace with the growth of the CSH network. As the hospital grows so does the financial commitment to the children served by CSH. Fundraising dollars need to grow.

- CSH's profile has raised awareness of its services throughout the state. This increased visibility has also drawn in new companies and, ultimately this should increase fundraising dollars. Increased funds will allow CSH to serve more children.

- Succession planning needs to be developed to ensure ongoing, consistent growth of CSH.

Focus Groups

PARENTS FOCUS GROUP

Participants on the Parents Focus Group represent the continuum of services provided by CSH including inpatient, outpatient and long-term care. There was a common theme regarding the issues that were raised, more specifically (see Appendix B for focus group Agenda and E for detailed responses):

- Waiting period to access services;

- Need for more support for the whole family;
- Better and more coordinated care and communication among the providers as well as providers with parents; and
- Conflicts with the educational system.

Included below are the key questions that were asked and samples of the responses that were reflective of more than one parent on the Council.

How did you learn about Children's Specialized Hospital?

It is critical that pediatricians are aware of CSH and the various services it offers for children with special needs. As important, there should be a far better understanding by pediatricians of all of the services provided by CSH rather than assuming it only provides care to children with special needs.

"....Pediatrician caught the language delay (Westfield) and referred us to CSH."

"....an orthopedic evaluation was done by a CSH doctor. I was referred to this doctor by my pediatrician."

While their child was a patient, parents reported being approached by social workers within an acute care hospital to advise them of the services of CSH.

"...lived in Ohio and then moved to New Jersey. We were admitted to an acute care hospital and then the social worker told us about CSH."

"...(learned about CSH) through a social worker at an acute care hospital and have now been involved with CSH for 18 years."

As is the case with many parents, those on the Advisory Council reported that they relied upon the recommendations of their friends, family and neighbors.

"....My son had a speech delay and an evaluation was done. I called others to check their experiences with CSH and they were positive experiences."

What obstacles have you encountered?

There were several issues that were raised in response to the question regarding obstacles.

- Wait time to access CHS services (up to an eight month wait reported);
- Better communication and coordination between and among doctors/care teams and parents; and
- Better response from the educational system.

Wait Time – It was acknowledged by some that there has been improvement with the wait time for a child to access services at CSH, however, the shortened timeframe still seemed too long.

"Had to wait a month for therapy to begin after discharge from Inpatient."

"…varied experiences. Initially seen right away and then speech services took six months."

"…had an eight month wait." (Reported by two participants)

Coordination & Communication – There was concern among many on the Parents Focus Group that providers were not effectively communicating and communication is critical to the coordination of care.

".....there is a need for increased communication between therapists in different specialties—a more coordinated, holistic approach."

"Parents have to really push for coordination. For example, have speech work with outpatient therapy…"

"Not everyone knows the case specifics and plan for the patients….issues are not clearly communicated."

"Some therapists at CSH actually include the whole family in the conversations. This practice needs to be spread throughout the organization."

Educational System - There was frustration expressed by some parents regarding the challenges they encountered when trying to navigate the school system to arrange services for their child or children.

"I have two children who need services…..the school says they offer services and that we don't need to go outside. I had to work the system and convince them that they need therapies outside to be able to excel in school. I was told 'that's medical based, this is academic-based and we're not accepting those evaluations.'

"I had to get three evaluations for my school."

"I wish someone could bridge/advocate for families in their relationship with the school systems. Currently the parent is forced to take on this expertise to bridge the gap and we don't have the expertise."

Are there services you would like to see that are not currently offered?

There was lengthy discussion regarding the needs of family members. More specifically, parents felt that not only should the child be treated but the family, as well. Parents talked about how difficult it can be for other kids within the family. In addition, they felt that there was much to be learned and comfort received from interacting with families in similar situations.

In summary, parents were simply saying they too needed support.

"In the best of worlds, parent concerns and worries about their other children and the entire family would be addressed. My psychological needs should be addressed, also. Perhaps a fee-based service provided for parents and addressing what they need."

"There was a parents group with a social worker when I first came. I would like to have a parents group facilitated by CSH."

"

*"There is a need to look at the entire family, especially in long-term care. Many families have long-term issues. It would be great if there was a psychologist available***.*** "

"…link with other families with similar experiences, diagnoses and conditions."

"I didn't know about family faculty until after we were discharged. I also didn't know about the Parents Advisory Council until I overheard someone talking about it."

"….there needs to be support groups and activities for kids as they grow older. We can't wait for Friday Night which starts at age 13."

Although not the dominant issue, a parent discussed her frustration with language barriers for the Latino population. She believed there was a need for a real person, not just a telephone interpreter service.

Often assessments only focus on their concerns or what needs improvement; however, there were positive comments, as well, for example, one parent felt very strongly about his experiences with CSH.

"All of my needs were met within inpatient for nine months and as outpatient for over three years. I haven't had a bad experience. An inpatient therapy team would huddle every morning and communicate with each other to make sure everyone knew what was going on. Even members who were not on the direct team would offer ideas to try. At Toms River, they still communicate ok but on a more informal basis. I was shocked at how well everyone communicated with each other.

I was appropriately "bugged" to make sure I was communicating with everyone also. I know one family that drives an hour and a half each way to receive specialty therapy treatment related to lung cancer. They wouldn't go anywhere else."

PHYSICIANS

The physicians participating in this group represented hospital-employed physicians and included those participating in a medical credentialing committee meeting. Further, they represented various specialties which provided valuable feedback. While specific questions were posed, the facilitator allowed the physicians to provide comments on issues/topics they felt were important. Comments provided by the Parents Focus Group were used, in part, to initiate the discussion (See Appendix A for focus group questions).

Parents have asked for more of a coordinated and communicative team approach to treating the patient. Is this approach standard?

"Teams of physicians do work together and communicate with each other regarding the patient."

"Outpatients are seen one-on-one in exam rooms on an episodic basis. If necessary, a social worker will be called in to meet with the parents and child."

"The family is there when the exam is completed allowing dialogue and involvement to be ongoing."

"For physiatry, communication is certainly the goal but these patients may see specialists at other facilities. Communication is not the easiest thing. Based on the goal, sometimes we are more successful than others."

Several parents spoke about the long waiting period for CSH services. Do you believe this is problematic?

"The waiting list is much shorter now. Appointments can be made within six to eight weeks. The excellence of our services is becoming more recognized in the community and demand is increasing. We are hiring more staff."

"We need to hire more specialists."

"Also training subspecialists. We need neurodevelopment specialists and Physical Development and Rehabilitation (PM&R). Our fellowship program in both Developmental and Behavioral Pediatrics and PM&R will help recruit more staff."

Are the wait times attributed to a lack of space and/or staffing?

"Space is always a valuable commodity but now it is the need for staff. The community base is sound. We can improve it but the obstacle is the waiting list."

Do you find that local physicians have a good understanding of the services you provide and are inclined to refer patients to CSH?

"With regard to inpatients, the community referral is from hospitals. Very few come from home."

"In physiatry, referrals are from PM&R community."

"I think they are aware. They are well aware of our services. The pediatricians are stretched for time and are under pressure to be financially independent. (This followed a comment that physicians have tried to go into pediatricians offices to provide education to the physician and his/her staff but success has been limited)."

If you had unlimited resources, would there be new programs and services you would want developed. Is it fine the way it is? What would you want to do differently?

"We have opened so many new sites including Bayonne, Clifton, Egg Harbor and Hamilton and we will be in Morristown and Beth Israel."

"It is a slow process to improve and enhance services."

"We need to be concerned about reimbursement."

CSH Conducted Survey Date

CSH SURVEYING

Prior to the start of the Community Health Needs Assessment, Children's Specialized Hospital conducted a survey that had previously been administered in 2004 and 2008. CSH staff and families utilizing the services of CSH were asked to respond to six questions. The objective, in part, was to determine if staff perceptions were consistent with those of the families. Three hundred and thirty one (331) families and 313 staff completed the survey. Some of the findings are as follows:

Does CSH focus on strengths of the child and family?

Families responded favorably (good and very good) in 2004, however there was a marked decline in 2008 from 78 percent to 54 percent respectively. Favorable responses were reflected once again in 2012 with 74.6 percent. It would be interesting to study the changes that occurred between 2004 and 2008 to determine what may have attributed to a less than favorable response from families as well as what occurred between 2008 and 2012 that reflected an improved score.

Does CSH support relationship building and community membership?

Clearly staff responses reflect a perception that there is ongoing improvement with an increase from 52 percent in 2004 and a reported 78.9 percent in 2012. The response is not as similar with families. They indicated 64 percent in 2004 and 63.5 percent in 2012. What is notable is that the highest score from parents was in 2008 with a reported 73 percent.

Does CSH foster mutual trust and respect between families and program staff and/or administration?

The responses to this question reflect a similar belief by families and staff. Families, (other than 2012 where there was a minimal difference) viewed CSH very favorably with scores over 80 percent.

Does CSH promote family choice and control?

Clearly families feel strongly that they do have family choice and control. In 2004 and 2008, they responded far more favorably than staff; families responded in the high 80th percentile with only a slight drop in 2012.

Does CSH offer families good information and access to information?

In 2004, staff rated itself significantly lower than did the families. Staff responded with 53 percent and families with 76 percent. In 2012, however, families rated CSH at 69.5 percent while staff were at 79.3 percent.

Does CSH include families in policy decisions and program planning?

There was a significant drop in percentages by families from 79 percent in 2008 to 57.1 percent in 2012. Even staff responded less favorably from 2004 with 86 percent to 66.4 percent in 2012.

Data from these surveys can be invaluable in focusing attention and resources on improving performance where responses were not as favorable and reinforce what is working well. Drilling down to a more in-depth analysis as to why staff and families feel the way they do can provide information that allows for further action. In fact, seeking more detailed information from survey respondents may be the only way in which specific changes/actions can be developed to improve upon performance. Absent this approach, it is sheer speculation about what has influenced responses; the exception may be if there were significant changes occurring to which responses can be attributed. The responses from families from this particular survey should be viewed along with the responses received by CSH's Parents Advisory Council which held a focus group session at the start of this initiative.

SURVEYS: EDUCATORS AND REFERRING PHYSICIANS

Two groups were surveyed by an on-line survey tool. The two groups surveyed were recommended in the course of the Parents Focus Group discussion comprised of members from CSH's Family Advisory Council. Parents shared that educators (Appendix C – Teachers Survey) and community physicians had, or should have, critical relationships with patients and families and there are ways in which these relationships can be enhanced. Feedback provided from the two survey groups will better identify strategies to work with educators and physicians in the best interest of parents and their children.

Surveys were distributed by CSH via email and financial incentives were provided including a $25 gift card for teachers responding to the survey and a $50 gift card to physicians. Responses were compiled for analysis.

Survey of Educators

To determine which schools/teachers would be surveyed, several CSH staff members were queried to provide the names of individuals and/or individual schools or systems. Selection was based on those individuals that have a relationship with CSH (negative or positive) and also included individuals/schools that CSH would like to establish a relationship with. Individuals, including school counselors, therapists, psychologists, case coordinators, among others, were sent a letter with instructions on how to

participate in the online survey. Letters were mailed to administrators, e.g., principals, executive directors of special education or student services for those schools where an individual that could be surveyed needed to be identified.

Letters were sent to twenty administrators and sixteen individuals for a total of 36. Administrators were asked to identify the appropriate individual to complete the survey. If a teacher received the survey but believed he/she was not the appropriate person to respond, the survey was forwarded accordingly.

Ten individuals completed the survey reflecting the following positions and responses:

Title	Number of Respondents
Psychologists	2
Administrators	1
Therapists	1
School counselor	3
Child study team coordinator	1
Social Worker	1
Learning Disabilities Team	1

A number of open-ended questions were asked and the following reflect some of the responses to those questions:

If you are experiencing an increase or decrease in the number of special needs students, please describe your experience

The responses to this particular question has demonstrated that there are some schools that are experiencing an increase while others have noticed that there are cycles in relation to the increase or decrease in their caseloads. Respondents noted:

- Children are younger
- More are reported as having anxiety
- Numbers of students with substantial disabilities that are not referred out to out of district placements have increased.
- Children in need of psychiatric support
- Greater number of students with ASD or symptoms that require diagnosis
- More students are coming directly from parents

"The number of special needs students fluctuate by year, some years they increase and some years they decrease but overall I have a large caseload of students."

"It is actually cyclical … it goes through cycles. We are actually seeing a few more youngsters. We

find that the most fragile students are those that come to us. The sending districts are tending to try and meet the needs of the students "in house" under many circumstances."

"We have had a decline for the past few years as the general population of the area has declined, but we are slowly increasing for the past two years by a few students per year."

"I am noting an increase in special needs students in my caseload. Approximately 20 of my students have IEP's - many of whom are classified Other Health Impaired and have been diagnosed with ADHD. Many have incredible difficulty with executive functioning skills. Additionally, I have noted a sharp increase in the number of students I see who experience anxiety."

"Not necessarily an increase in special needs students but an increase in the number of special needs students with substantial disabilities that are no longer referred out to out of district placements."

"I am on the Preschool Child Study Team. We are having a large number of referrals from our preschools, and the number has increased each year. We are also having a lot more children referred who have diagnoses of Autism or are diagnosed as we are testing or shortly after."

"Greater number of students with ASD or symptoms that seek diagnosis. Several elementary school children in past 12 months who are in need of psychiatric support. Parents who are in need of understanding of diagnosis and support with day to day living with special needs children"

"...In one elementary school alone we evaluated 18 students for special education eligibility and 16 were found to be eligible, last school year."

"I work in a middle school and it appears that this year we are receiving more new referrals than usual. They are also often coming from parents directly rather than staff or our Intervention and Referral Services Committee."

If your funding to provide services to special needs children has been impacted, please describe what you have experienced.

Most respondents reported experiencing less funding with increased numbers of students needing services. The result has been fewer students being referred out as well as cuts in services. Some reported significant cuts in previous years but more flexibility with current budgets. It's noteworthy that two indicated that cuts in funding are not an issue for their school.

"Overall throughout the state funding has decreased over the years. Transitioning children with severe disabilities has become increasingly difficult due to programs being shut down and funding

cuts everywhere. Specifically, in my school I have not seen the effect as much as I see it at a state-wide level but the problem remains the same."

"Fewer students are being sent to Out of District schools which means they are in programs within our building but are really struggling without the therapeutic environment. Ongoing counseling is not really an option in our environment."

"Yes, it has. We are experiencing larger class sizes and not as much individualized attention for students"

"funding hugely impacted. My district is creating programs to "keep" students within district that they would have normally referred out."

"We have basically the same amount of $ but larger population with greater needs."

"We have been told that we need to be mindful of the funding when thinking about placement because funding is sparse."

"Our funding has been impacted by the overall reduction in funds to education. This has meant cuts to services our district can provide. About two years ago, the cuts were deep, it appears that there is a little more flexibility with budgets at this point in time. We have been able to consider more options for our students with special needs."

Are you familiar with Children's Specialized facilities, services or programs?

Those that reported budget cuts were not having an impact on their school did report having an awareness of Children's Specialized. As important, there is an interest in learning more about CSH.

"Some of our students come from Children's specialized hospital"

"I would love to know more of your programs and services to recommend to families within our district. I will say that many do already work with you, and though I don't necessarily refer to your programs, many parents come in with information from Children's Specialized. "

"As a public school employee I cannot directly refer to CSH for services, but CSH is on our list that we give parents as a place they can go for evaluations and/or therapy."

When working with Children's Specialized, have you been pleased with the services and support provided by staff?

Not all comments directly respond to the question regarding whether they are pleased with their interaction with CSH. In fact, only one respondent expresses frustration as it relates to wait times for appointments. More positively, one respondent indicated an interest in communication with CSH, more specifically, CSH's psychiatrists.

> *"As previously described, I can't recall working directly with staff from Children's Specialized. My contact has been limited to providing Vanderbilt scales to your doctors …"*

> *"I would like to have more communication with outside therapists. It is very difficult to communicate with any psychiatrist."*

> *"Long wait for initial appointment for new client Psychiatrist who does not always understand needs of client Some difficulty accessing families from southern Ocean County to Toms River"*

Have your students had to wait for a period of time to gain access to the services/programs of Children's Specialized?

> *"Specifically for appointments there has been a substantial waiting period."*

> *"bilingual evaluations, neurological/developmental pediatric evaluations*

> *"Autism Team seems to take minimum of 6 months"*

> *"Parents have commented that there is a lengthy wait to get a neurologist appointment."*

What obstacles. if any, have you encountered when reaching out to Children's Specialized on behalf of your student(s)?

Six of the respondents indicated that they hadn't experienced obstacles as they have not had contact with CSH. Those that had experience cited problems with wait times for appointments, communication and securing copies of evaluations.

> *"In past experience, an extended wait time for students to get appointments with specialists"*

> *"Our experience has been mostly with nursing staff who work with the students that are sent here to program."*

"Communication can sometimes be tough due to scheduling conflicts, etc."

"It is difficult to get copies of evaluations, even with parent consent forms Signed and faxed over"

"I haven't encountered any obstacles because the parents are given the referral to reach out on their own."

"Difficult to find direct phone number to connect with live person to answer questions"

Are the families that you have referred to Children's Specialized pleased with the services received? Please describe below.

Four of the respondents had no comment. Some of the comments could use further explanation, for example, a reference to parents being pleased but cautious about recommending. The basis of a parent's need to be cautious would be of greater value if why they were cautious had been explained.

"For the most part yes. Some did question the effectiveness of the therapies offered."

"I only have one student, and he family is pleased"

"I think the families are pleased with the staff and services. There have been occasions when a parent comes back to us with a prescription for a Section 504 plan, but that is for the school's Section 504 committee to determine, not for a doctor to automatically prescribe ... lf it is recommended, then recommended accommodations that should be in the plan should also be given. (Sorry, this probably should have been under the previous question about obstacles I've encountered.")

"yes"

"Yes, I generally get positive feedback after families go to CSH."

"Combination of pleased and cautious about recommending"

Please share, if applicable, any new services or programs that you would like Children's Specialized to offer to better meet the needs of your students.

The reference to the respondent having very limited knowledge of services or programs provides an opportunity to develop/distribute information and educational resources to better educate teachers about CSH.

"Therapies that would incorporate high interest level activities for high school students."

"Early intervention parents need a place to go to get braces and adaptive equipment as it is very hard to get vendors to come to the house. We could also use a local orthopedist besides the one from DuPont, where families could get seen and get x-rays when they have limited transportation.

"I am in a desperate search for more services, programs, therapists who specialize in anxiety disorders."

"more groups for tweens. More support for dx: of anxiety"

"Social Skills groups; therapeutic nursery program"

"Clearer understanding of services in new facility in Egg Harbor Twp. More evening hours for working parents"

"I have very limited knowledge of services or programs that Children's Specialized offers to students."

Please share any specific programs and/or services that FAMILIES you have referred would like Children's Specialized to offer.

"I am speculating, but probably services dealing with anxiety issues and help with executive functioning/ADHD issues."

"social skills groups, parents' workshops, therapeutic nursery"

"Social skills group in southern Ocean County or nearby Any summer programming that is affordable or has grants for needy families"

"Because I have limited knowledge of programs offered by Children's Specialized, I have not referred any families."

Please share anything specific Children's Specialized Hospital should be doing to better support you in meeting the needs of your students.

In addition to requesting/recommending needed services and programs, there is a consistent themes to the comments provided by respondents, specifically,

- There is a need for more information so there is a better understanding of the programs and services provided by CSH.

- There should be greater teacher involvement prior to initiating formal reports and recommendations.

  "…high interest level activities for older adolescents."

  "Meeting times are somewhat difficult to accommodate staff from CSH"

  "working together with primary therapists would be great- have not had much experience yet, but so far the outreach by your PT's is appreciated"

  "Perhaps requesting specific information and feedback from the school/teachers when doing an intake for a student to get the whole picture of the child, not just the parent report."

  "better understanding of the school environment prior to writing a list of school recommendations that are nearly impossible to implement"

  "workshops for parents"

  "I don't know how this can be resolved, but offering shorter waiting periods for appointments."

  "With signed request from parent, District could receive reports directly seeking teacher input regarding child's classroom behaviors and academic progress"

  "Is it possible to do mailings to school districts in order to learn about the programs offered by Children's Specialized Hospital? This information can then be used to inform parents of the programs."

Survey of Referring Physicians

CSH's Director of Referral Development/Admissions provided a cross section of inpatient (IP) and outpatient (OP) referral sources with representation from different geographic regions in the state of New Jersey. Letters were sent to 32 IP referral clinicians and 37 OP referral clinicians. The IP referral sources included physicians, nurses, a nurse practitioner and a social worker. The OP referral sources were all physicians.

Out of the total of 69 letters sent out, 16 surveys were completed as follows:

Inpatient referral sources	
Social Worker	3
RN	3
Physician	2
Unknown	3

Outpatient referral sources	
Physicians	4
Anonymous	1

There were general findings resulting from survey responses. More specifically, most physicians responding to the survey indicated they have referred to CSH. Eleven of the 16 respondents indicated that they were very familiar with CSH and only one indicated he/she was not familiar with CSH or its services and programs. Of the 16 respondents, 12 were very pleased with the services and support by staff while four were somewhat pleased. And finally, 14 responded to the question regarding wait times with seven having experienced a wait and seven others reporting no wait.

These general responses are helpful to see the larger picture regarding physicians' knowledge of CSH, its services and programs and the challenges they may encounter when interacting with CSH. Of greater value are the detailed comments provided that drill down to specific "issues" that identify strengths and weaknesses with operations and services. The following reflect general categories that encompass these strengths and opportunities for improvement. Only a selection of comments have been used to support the need to further examine areas for improvement. A complete list of comments is included in Appendix D.

STRENGTHS IDENTIFIED BY PHYSICIANS:

Reputation of CSH – While there were comments that focused on areas that need to be examined or improved upon, there was no question that CSH enjoys a remarkable reputation within the New Jersey healthcare community.

> "Generally (CSH) well regarded, the Kessler for little people."
>
> "Top notch. It has a great reputation for highest quality rehab services."
>
> "Outstanding rehab and long term care. Motivated to get children back home with their families and to teach family members how to best care for their children."

Recognition of Specific Department/Staff – Normally assessment do not incorporate information regarding specific staff, however, the staff names referenced in the comments appeared throughout so many of the comments provided.

"Very pleased with Admissions Director & Coordinators."

"Morristown Medical Center has a very good relationship with the admissions staff at Children's Specialized Hospital. The CSH Admissions staff is always responsive & helpful regarding referral for our hospital."

"I have been pleased with the Referral Staff. Sharon D'Antonio is fantastic and responsive…"

"Admission procedure is fantastic."

Barbara Marrone has been wonderful as a nurse liaison between our facility and Children's…"

"Sharon D'Antonio is a pleasure to work with."

"The employees at CSH are very helpful with doing a referral. Sharon D'Antonio is very helpful."

"…Barbara Marrone has a quick response time, and if she is not available, Jeanne Brooks & Sharon D'Antonio are more than helpful."

"I have never encountered any obstacles; their admission dept. is very accommodating both to our institution and to our families."

In response to questions, there were several areas that created some concern, frustration and/or challenges for the providers. The comments provided are organized by general areas that require more in-depth analysis by CSH.

Capacity – There were numerous comments regarding the ability to place patients on an inpatient basis or arrange for services for outpatient or long term care.

"Availability of appointments for inpatient beds" (barriers encountered)

"Especially for outpatient referrals" (required to wait to arrange for services)

"….the situation is very different for long-term care placement at Mountainside and more beds are necessary to meet need." (no problems encountered with placement of acute inpatient rehab beds.)

"Occasionally we have to wait days to weeks for an inpatient but when it is an emergency it has always worked out. Scheduling of outpatient services can be challenging."

"Bed availability is sometimes tight."

"Improve bed capacity in both facilities, acute rehab & long term care." (what CSH can be doing better to meet the needs of physicians.)

Communication with Physicians –

"Increased information sharing possibly in the form an EMR or chart for transfers back to the hospital from both the acute and long term care areas."

"....we also had been told that we would be receiving frequent status and progress updates, which has not occurred."

"Further status updates regarding referred patient progress, discharge planning, etc. Often times the ICU physicians and staff who worked so hard to resuscitate and stabilize these patients have no further communication and lack updates regarding the outcomes of their patients." (what CSH can be doing to better meet the needs of physicians)

"Keep the primary physician well informed on the progress of the patient in all the aspects of the treatments and prognosis of the disease."

Patient Care - There were concerns raised by physicians regarding the care provided by the nursing staff. Some comments reflected concerns brought to the physician's attention by the parents of a patient at CSH.

"....Have received complaints from former patients about nursing."

"Referrals and responsiveness are not a problem. The issue may be regarding care delivery."

"....Some parents have commented that they felt nursing could be better i.e., more available and/or responsive, especially on weekends (New Brunswick locations). I have also heard complaints about the nursing in the long term care unit that not enough attention was being paid to the patients."

"Families overall have been very happy. Only concern has been from more medically complicated patients who are concerned that medical problems seem to stress out staff/nurses."

".....I have not been pleased on a few occasions with the reports and the quality of the care that we hear from our referred patients. I called the Nursing Manager that evening and she did not seem very interested in approaching the family or fixing the issues."

Finance – Providers continue to face challenges with managed care and their ongoing requirements for authorizations, additional documentation, etc. Providers identified this area as one where CSH could provide greater support.

"...My only request would be that the financial dept. at Children's be able to offer more assistance in obtaining authorization for transfer to Children's." I am a social worker that covers a 55-bed NICU; the times it takes to obtain auth takes away from svcs. I could be providing to their families. Any assistance the financial dept. at Children's could provide would be beneficial."

"Obtaining authorization from insurance. Although CSH has a finance dept. and I hear from insurance companies all the time that they need to speak with them, I feel that all the ownership is place on the transferring hospital to obtain auth."

Transportation – It would appear from responses that transportation of patients and/or parents has been problematic, although some respondents indicated that it has since been resolved. Many of the suggestions for additional programs and services reference transportation for specific types of patients and from specific facilities. For example, the following comment was made regarding transportation:

"Transport services back to CSH after hospitalization for long term care patients as Logisticare refuses to transport an unaccompanied minor. This often times delay transfer until a family member can be available. Ability to transfer patients back to long term care on weekends."

Perhaps posing this specific question directly to parents may provide more detailed information to determine if needs are being met by the current transportation services.

Provider Recommendations - Valuable information was collected in response to a question requesting additional programs or services that CSH should offer that would meet the needs of the provider as well as the patients he/she serves. The following reflect most of those recommendations:

"Further development of a comprehensive adolescent in-patient Chronic Illness Program which would include family therapy, psychiatry, plus medical/rehab/education with a transition piece and follow-up on discharge. This could be modeled on Cumberland Hospital for Children and Adolescents n New Kent, Virginia. It is a hardship for children and families to have to travel so far from New Jersey for this service and transition and linkage into community services afterwards is

problematic. New York State families could also benefit from having this service nearby and provide a further source of referral."

"PICC line/port a catch care; we also had been told that we would be receiving frequent status and progress updates, which has not occurred.

"Nothing in particular comes to mind other than accepting cognitively impaired young adults who are greater than 18 years of age."

"Adding transportation for families was a huge gift for our families. Waiting for a DVD that we can play for the families to introduce them to the facility & the available services."

"Neurodevelopment program."

"I think a Ronald McDonald House would be very helpful so parents can stay as long as they want. I am aware that the parents are allowed to stay, but it would be nice to have a place to go to."

"Assistance with the transition into the community."

"I would appreciate receiving discharge summaries for the patients the trauma service refers to CSH."

RECOMMENDATIONS

Parents

- Develop communication tools to distribute to all families regarding support programs and/or services for families, such as "Family Faculty." Consider providing programs just for children that are within families with a child that has special needs – a more holistic approach to treating the child and his/her family.

- Parents expressed concern with the social worker to patient ratio for outpatient services. If forming a focus group to further explore coordination of care, parents should be asked about this particular concern. More specifically, is it truly a matter of a social worker having a far too large patient caseload or is it the coordination of care that is creating frustration?
-

Providers

- Based on feedback, there is a distinction between the team-managed/coordinated care for inpatients and that for outpatients. Physicians indicated that there is a team approach to managing the care of inpatients, however, that does not appear to be the case for outpatients. Parents expressed frustration with the lack of communication and coordination of their child's care. The physician focus group noted during their discussion that it is far more difficult to coordinate care for a child with special needs as they are receiving care from healthcare providers that are not affiliated with CSH; clearly this can create a challenge to a "team" approach. Despite the obstacles, a focus group of parents with children receiving outpatient CSH services should be convened to discuss what the challenges are and ask them to assist in developing possible solutions to the barriers that are currently being encountered. In addition, a small sample of physicians within communities that are providing services to children also being served by CSH should be contacted and their feedback solicited as to how care could be better coordinated.

- The Physician Focus Group as well as one Key Informant noted that there was a scarcity of pediatric neurologists which, in turn, resulted in demand far exceeding the supply of this specialized care needed and requested by families. In fact, a report released by the Children's Hospital Association found (through a May 2012 survey) that pediatric specialist shortages that most affect children's hospitals' ability to deliver care are:
    - Pediatric Neurology
    - Developmental Pediatrics/Behavioral Medicine
    - Pediatric Gastroenterology
    - Pediatric Surgery
    - Pediatric Neurosurgery

The study further indicates the most frequently reported vacancies of 12 months or longer within children's hospitals are:

- Pediatric Neurology
- Pediatric General Surgery
- Developmental Pediatrics/Behavioral Medicine
- Pediatric Gastroenterology
- Pediatric Pulmonology
- Pediatric Rheumatology

- Physicians were asked via the survey if there were any new services and/or programs that they would like CSH to offer to better meet the needs of their patients. The following reflect the specific recommendations:

  - Increased information sharing possibly in the form of an EMR or chart for transfers back to the hospital from both the acute and long term care areas.
  - Provide the ability to transfer patients back to long term care on the weekends. Logisticare will not transfer an unaccompanied minor and this creates a delay until a family member is available.
  - Further develop comprehensive adolescent in-patient chronic illness programs that would include family therapy, psychiatry plus medical/rehab/education with a transition piece and follow-up on discharge.
  - Provide a DVD that can be shared with parents to introduce them to CSH.
  - Transportation to out-patient services as well as PT and OT
  - Address bed capacity as it remains an issue.
  - Keep the primary physician well informed on the progress of the patient in all aspects of the treatment and prognosis of the disease.

  It was mentioned by a CSH physician that a strategic planning process is under way. The recommendations referenced above should be taken into consideration in that process. If some of the recommendations have already been addressed, then a communication plan should be developed to share this information with community providers.

- Physicians responding to survey questions commented on nursing, more specifically, that parents had commented that nurses were stressed, did not seem responsive or concerned, among other comments. These responses may serve as a starting point to educate nurses as to how they are being perceived and those perceptions can be changed.

- Pediatricians play a critical role in referring children with special needs to CSH. A survey administered to referring physicians indicated there was a high regard for the services provided by CSH and clearly an awareness of the services CSH offers. However, this was a relatively small sample and the more challenging group are those pediatricians that are not referring children either because they are not aware of CSH and its services or they are aware, but are not inclined to refer to CSH (for whatever reason). Doctors participating in the physician focus group indicated that attempts had been made to better educate pediatricians and their staff as to how children with special needs can be identified and how CSH can meet their needs. The challenge they experienced is that education of staff had to take place within a very limited amount of time (lunch break). This restriction did not provide enough of an opportunity to ensure there was a true understanding of needs and the services available by CSH to address these needs.

Education

- Develop curriculum that could be offered for Continuing Education Credits at the state nurses' conference. This process needs to start long before the conference program is announced, however, with the appropriate course offering, CEUs can be awarded and this will provide the time and incentive for nurses (especially market to those nurses that work within pediatric offices) to attend such a program.

- Recognizing that physicians must attain a specific number of CEUs to maintain their licenses, the Medical Society of New Jersey often offers programs for Continuing Education Credits. Physicians must complete 100 credits of continuing medical education at least 40 of which must be Category I and up to 60 of which can be Category II and both categories are recognized American Medical Association as medical education courses. While standards for the CME subject matter and content are developed by the Board of the AMA, other programs offered by national or state organizations that accredit education programs may be recognized by the AMA. Partnering with the Medical Society of New Jersey to develop and offer courses regarding medical care for children with special needs may allow CSH to reach a much larger community of physicians.

Demographics

- Hudson, Passaic and Union counties have a relatively large population of Hispanics and Latinos. A concern was raised by a parent at the Parent Advisory Focus Group session that there were not enough resources or responsiveness to the Hispanic population. CSH now has an opportunity to reexamine the various literatures that are available in Spanish and ensure the availability of interpreters to meet the needs of this population. A certification program had been offered by the New Jersey Hospital Association's Health Research and Educational Trust to identify and certify

hospital staff to serve as medical interpreters. CSH should research if both the program and resources continue to be available.

- There were several counties that had particularly high numbers of children with disabilities; however, there was not a CSH site of services within these areas. It is not realistic for CSH to provide programs and services in every county; however, it should be examined more closely to ensure that those children residing within those counties, i.e., Essex and Camden have access to CSH services, particularly when transportation and financial resources are limited. As important, referral patterns by pediatricians within these counties should be examined to determine if these children are even receiving information let alone referrals to CSH. Further education for pediatricians and their staffs may address some of the problems.

- Within specific geographic areas, there were noticeably high numbers of Asians and yet the numbers served by CSH were remarkably low. What is not clear is whether this particular population experiences significantly lower numbers of children with disabilities and special needs than others, such as whites and African Americans. This should be explored in greater depth.

Services

- There are many hospitals that have identified themselves as children's hospitals including:

    - Children's Hospital at St. Peter's
    - K. Hovnanian Children's Hospital (Meridian Health System)
    - Children's Hospital of New Jersey (Saint Barnabas Healthcare System)
    - Goryeb Children's Hospital at Morristown (Atlantic Health System)
        - Goryeb Children's Center at Overlook Medical Center
    - St. Joseph's Children's Hospital
    - The Joseph M. Sanzari Children's Hospital (Hackensack University Hospital)
    - Children's Hospital of New Jersey (University Hospital)
    - The Children's Hospital of Philadelphia (CHOP)

    Some of these hospitals may, in fact, be treating children within those areas that CSH does not currently offer services, however, what remains unclear is if their programs are truly integrated, comprehensive pediatric rehabilitation centers. Absent this assurance, it begs the question of whether children are receiving the appropriate and quality level of care they need.

- When analyzing financial data, it was apparent that many patients were not identified by a race or it was simply noted "unknown." To ensure a true and accurate picture of the patients being served by

CSH, training for intake staff should be considered. Tools and resources for such training are available through the New Jersey Hospital Association's Health Research and Educational Trust. Absent more complete responses, it is difficult for CSH to get a true and accurate picture of the various populations it is serving.

- There were repeated comments regarding nursing care. These comments were shared by referring physicians as they received feedback from families they referred to CSH. There was no feedback from the Parents Focus Group, however, it may be appropriate to use the comments as the basis of a discussion to determine how services and/or perceptions can be addressed.

APPENDICES

APPENDIX A

Children's Specialized Hospital
Focus Group Meeting
October 4, 2012
Physician Group

I. Overview of Needs Assessment/Purpose of Focus Group

II. Questions

- Do you find that the local physicians have a good understanding of the services you provide and are inclined to refer patients to CSH?
- Feedback from parents indicating that many had a significantly long wait to get into your system. Do you believe there are specific solutions to accelerate the period of time it takes to move a child into your system?
- Parents also talked about a holistic approach to caring for the whole family rather than just the child. Is this realistic? If not, what would be needed to facilitate such an approach? If yes, how can it be assured that this is followed throughout the organization?
- What services and/or programs do you believe are functioning well and what could be improved upon?
- What would you need to develop the ideal programs/services?

III. Next Steps In the Process– Conclude the Meeting

APPENDIX B

Children's Specialized Hospital
Focus Group Meeting
October 4, 2012
Physician Group – Excerpt from Medical Staff Meeting Minutes

Community Needs Assessment: Valerie Sellers, of AMK Healthcare Consulting, attended today's meeting and conducted a question and answer focus group session. She stated that this is not a government requirement, but Amy Mansue felt it important to understand the needs of the community. Ms. Sellers met with parents and will meet with two other groups. The objective is to pose questions and get feedback. This is an attempt to find out what works well, and what can be done to make improvements. Do you believe that programs and services are functioning properly? We are looking at efficiency of programs and services. All answers will be anonymous and will be incorporated in a larger report. What can be done differently?

Doctor: What do parents mean by "treating the whole family?"

Ms. Sellers: How do parents communicate challenge in the home environment?

Doctor: For outpatient services, families would like after school patient services.

Doctor: The waiting list is much shorter now. Appointments can be made within 6 to 8 weeks. Excellence of our services is becoming more recognized in the community. Demand is increasing. We are hiring more staff.

Doctor: We need to hire more specialists.

Doctor: Also training subspecialists. We need neuro-developmentalists and PM&R. Our fellowship program in both Developmental and Behavioral Pediatrics and PM&R will help recruit more staff.

Ms. Sellers: Is it a function of space? Staffing?

Doctor: Space is always a valuable commodity, but now it is the need for staff. The community base is sound. We can improve it, but the obstacle is the waiting list.

Doctor: In Physiatry, references from PM&R community.

Doctor: With regard to inpatients, the community referral is from hospitals. Very few come from home.

Doctor: There is always conflict with length of therapy service. Schools provide services that are medically necessary only, and usually for short periods of time.

Doctor: Can't get funding for level of care.

Ms. Sellers: Do you think part of the challenge would be addressed through education with the school system?

Doctor: Based on school parameters, some models are different. There are funding limitations for services.

Ms. Sellers: We talked about holistic approach and waiting time. Do the pediatricians in the community understand what you do and how they can bring children to our facility?

Doctor: I think they are aware. They are well aware of our services. The pediatricians are stretched for time and are under pressure to b financially independent.

Ms. Sellers: Broader question… If you had unlimited resources, would there be new programs and services you would want developed? Is it fine the way it is? What would you want to do differently?

Doctor Three: It is a slow process to improve and enhance services. There is a continuum of looking and checking to expand or provide new services.

Doctor: mentioned all of our new sites – Bayonne, Clifton, Egg Harbor, Hamilton He stated that we will also be with Morristown and Beth Israel.

Doctor: Need to be concerned with reimbursement.

Ms. Sellers: A question related to parents… A team approach with doctors and social workers. Is that standard?

Doctor: For inpatient, we do have that approach with various teams

Doctor: Outpatients are seen one on one in exam rooms. On episodic basis, we may call a social worker to come in.

Doctor: The family is there when exam is done. Dialogue and involvement is ongoing.

Doctor: For Physiatry, communication is certainly the goal, but these patients may see specialists at other facilities. Communication is not always the easiest thing. Based on the goal, sometimes we are more successful than others.

Ms. Sellers indicated that her data analysis will look at types of patients served. Data will be looked at with feedback from our staff, realistic vs. not realistic. Two other focus groups will be referring pediatricians and representatives from the school district. Similarities will be looked at. Ms. Sellers applauds Amy Mansue and the hospital for doing this, which was strictly voluntary.

APPENDIX C

SurveyMonkey

Children's Specialized Hospital - Community Needs Assessment

1. What is your primary role within your school or system?

	Response Percent	Response Count
Therapist	10.0%	1
Social Worker	10.0%	1
Psychologist	20.0%	2
Teacher	0.0%	0
Administrator	10.0%	1
Other (please specify)	**50.0%**	**5**
	answered question	**10**
	skipped question	**0**

2. If you are experiencing an increase or decrease in the number of special needs students, please describe your experience.

	Response Count
	10
answered question	**10**
skipped question	**0**

3. If your funding to provide services to special needs children has been impacted, please describe what you have experienced.

	Response Count
	10
answered question	10
skipped question	0

4. Have you worked (referred parents) with Children's Specialized Hospital?

		Response Percent	Response Count
Yes		50.0%	5
No		50.0%	5
	answered question		10
	skipped question		0

5. If no, are you familiar with Children's Specialized facilities, services or programs?

		Response Percent	Response Count
Very familiar		33.3%	2
Somewhat familiar		33.3%	2
Not familiar		33.3%	2
	Comment		3
	answered question		6
	skipped question		4

6. When working with Children's Specialized, have you been pleased with the services and support provided by staff?

		Response Percent	Response Count
Very pleased		**40.0%**	**4**
Somewhat pleased		20.0%	2
Not pleased		0.0%	0
N/A		**40.0%**	**4**
		Please Describe	3
		answered question	**10**
		skipped question	**0**

7. Have your students had to wait for a period of time to gain access to the services/programs of Children's Specialized?

		Response Percent	Response Count
Yes		**40.0%**	**4**
No		20.0%	2
N/A		**40.0%**	**4**
		If yes, please describe	6
		answered question	**10**
		skipped question	**0**

8. What obstacles. if any, have you encountered when reaching out to Children's Specialized on behalf of your student(s)?

	Response Count
	10
answered question	10
skipped question	0

9. Are the families that you have referred to Children's Specialized pleased with the services received? Please describe below.

	Response Count
	10
answered question	10
skipped question	0

10. Please share, if applicable, any new services or programs that you would like Children's Specialized to offer to better meet the needs of your students.

	Response Count
	10
answered question	10
skipped question	0

11. Please share any specific programs and/or services that FAMILIES you have referred would like Children's Specialized to offer.

	Response Count
	10
answered question	10
skipped question	0

12. How well known do you believe Children's Specialized and the services it offers are in the school/educational community?

	Response Percent	Response Count
Very well known	10.0%	1
Somewhat known	**40.0%**	**4**
Name familar, but not services	20.0%	2
Not well known	30.0%	3
Other (please specify)	0.0%	0
answered question		10
skipped question		0

13. Please share anything specific Children's Specialized Hospital should be doing to better support you in meeting the needs of your students.

	Response Count
	10
answered question	10
skipped question	0

14. Please provide your name and contact information below so that we may send a $25 American Express gift card in appreciation for your time and feedback. Your information will not be used for any other purposes and will not be shared as part of the reporting of our findings. Deadline for survey completion is DECEMBER 24, 2012. Thank you for completing this survey as part of our Community Needs Assessment effort!

		Response Percent	Response Count
Name:		**100.0%**	**10**
School/System:		90.0%	9
Address:		**100.0%**	**10**
Address 2:		20.0%	2
City/Town:		**100.0%**	**10**
State:		**100.0%**	**10**
ZIP:		**100.0%**	**10**
Country:		90.0%	9
Email Address:		**100.0%**	**10**
	answered question		**10**
	skipped question		**0**

Page 2, Q1. What is your primary role within your school or system?

1	School Counselor	Dec 7, 2012 9:49 AM
2	school counselor	Dec 7, 2012 8:21 AM
3	School counselor	Dec 7, 2012 7:41 AM
4	Child Study Team Coordinator, Social Worker	Dec 6, 2012 1:25 PM
5	Learning Disabilities Teacher-Consultant	Dec 6, 2012 11:21 AM

Page 3, Q2. If you are experiencing an increase or decrease in the number of special needs students, please describe your experience.

1	The number of special needs students fluctuate by year, some years they increase and some years they decrease but overall I have a large caseload of students.	Dec 17, 2012 7:27 AM
2	It is actually cylicular ...it goes through cycles. We are actually seeing a few more youngsters. We find that the most fragile students are those that come to us, The sending districts are tending to try and meet the needs of the students "in house" under many circumstances.	Dec 10, 2012 1:58 PM
3	We have had a decline for the past few years as the general population of the area has declined, but we are slowly increasig for the past two years by a few students per year.	Dec 10, 2012 5:37 AM
4	I am noting an increase in special needs students in my caseload. Approximately 20% of my students have IEP's...many of whom are classified Other Health Impaired and have been diagnosed with ADHD. Many have incredible difficulty with executive functioning skills. Additionally, I have noted a sharp increase in the number of students I see who experience anxiety.	Dec 7, 2012 9:52 AM
5	An increase.	Dec 7, 2012 8:21 AM
6	Not necessarily an increase in special needs students but an increase in the number of special needs students with substantial disabilities that are no longer referred out to out of district placements.	Dec 7, 2012 7:43 AM
7	I am on the Preschool Child Study Team. We are having a large number of referrals from our preschools, and the number has increased each year. We are also having a lot more children referred who have diagnoses of Autism or are diagnosed as we are testing or shortly after.	Dec 7, 2012 6:01 AM
8	Greater # of students with ASD or symptons that seek diagnosis. Several elementary school children in past 12 months who are in need of psychiatric support Parents who are in need of understanding of diagnosis and support with day to day living with special needs child/ren	Dec 6, 2012 1:25 PM
9	I am experiencing an increase in the number of special needs students. In one elementary school alone we evaluated 18 students for special education eligibility and 16 were found to be eligible, last school year.	Dec 6, 2012 1:21 PM
10	I work in a middle school and it appears that this year we are receiving more new referrals than usual. They are also often coming from parents directly rather than staff or our Intervention and Referral Services Committee.	Dec 6, 2012 11:22 AM

Page 4, Q3. If your funding to provide services to special needs children has been impacted, please describe what you have experienced.

1	Overall throughout the state funding has decreased over the years. Transitioning children with severe disabilities has become increasingly difficult due to programs being shut down and funding cuts everywhere. Specifically, in my school I have not seen the effect as much as I see it at a state-wide level but the problem remains the same.	Dec 17, 2012 7:31 AM
2	This is not an issue at our facility.	Dec 10, 2012 1:58 PM
3	no impact personally but funding for personal equipment- wheelchairs etc has been tough to get	Dec 10, 2012 5:38 AM
4	Fewer students are being sent to Out of District schools which means they are in programs within our building but are really struggling without the therapeutic environment. Ongoing counseling is not really an option in our environment.	Dec 7, 2012 9:55 AM
5	Yes, it has. We are experiencing larger class sizes and not as much individualized attention for students.	Dec 7, 2012 8:23 AM
6	funding hugely impacted. My district is creating programs to "keep" students within district that they would have normally referred out.	Dec 7, 2012 7:44 AM
7	NA	Dec 7, 2012 6:01 AM
8	We have basically the same amount of $ but larger population with greater needs.	Dec 6, 2012 1:26 PM
9	We have been told that we need to be mindful of the funding when thinking about placement because funding is sparce.	Dec 6, 2012 1:23 PM
10	Our funding has been impacted by the overall reduction in funds to education. This has meant cuts to services our district can provide. About two years ago, the cuts were deep, it appears that there is a little more flexibility with budgets at this point in time. We have been able to consider more options for our students with special needs.	Dec 6, 2012 11:25 AM

Page 5, Q5. If no, are you familiar with Children's Specialized facilities, services or programs?

1	Some of our students come from Children's specilaized hospital	Dec 10, 2012 1:59 PM
2	I would love to know more of your programs and services to recommend to families within our district. I will say that many do already work with you, and though I don't necessarily refer to your programs, many parents come in with information from Children's Specialized.	Dec 7, 2012 9:59 AM
3	AS a public school employee I cannot directly refer to CSH for services, but CSH is on our list that we give parents as a place they can go for evaluations and/or therapy	Dec 7, 2012 6:02 AM

Page 6, Q6. When working with Children's Specialized, have you been pleased with the services and support provided by staff?		
1	As previously described, I can't recall working directly with staff from Children's Specialized. My contact has been limited to providing Vanderbilt scales to your doctors...	Dec 7, 2012 10:00 AM
2	I would like to have more communication with outside therapists. It is very difficult to communicate with any psychiatrist.	Dec 7, 2012 7:45 AM
3	Long wait for initial appointment for new client Psychiatrist who does not always understand needs of client Some difficulty accessing families from southern Ocean County to Toms River	Dec 6, 2012 1:28 PM

Page 7, Q7. Have your students had to wait for a period of time to gain access to the services/programs of Children's Specialized?		
1	Specifically for appointments there has been a substantial waiting period.	Dec 17, 2012 7:33 AM
2	not sure	Dec 10, 2012 5:39 AM
3	I wouldn't really know. I don't often hear from the parents that you are working with how long it took for them to get in for an appointment.	Dec 7, 2012 10:01 AM
4	bilingual evaluations, neurological/developmental pediatric evaluations	Dec 7, 2012 6:03 AM
5	Autism Team seems to take minimum of 6 months	Dec 6, 2012 1:28 PM
6	Parents have commented that there is a lengthy wait to get a neuologist appointment.	Dec 6, 2012 1:24 PM

Page 8, Q8. What obstacles. if any, have you encountered when reaching out to Children's Specialized on behalf of your student(s)?		
1	In past experience, an extended wait time for students to get appointments with specialists.	Dec 17, 2012 7:34 AM
2	N/A, Our experience hsa been mostly with nursing staff who work witht the students that are sent here to program.	Dec 10, 2012 2:01 PM
3	none	Dec 10, 2012 5:39 AM
4	Personally, I have not had any problems, as I haven't reached out.	Dec 7, 2012 10:10 AM
5	I have not worked with Children's Specialized Hospital	Dec 7, 2012 8:23 AM
6	Communication can some times be tough due to scheduling conflicts, etc.	Dec 7, 2012 7:46 AM
7	It is difficult to get copies of evaluations, even with parent consent forms signed and faxed over	Dec 7, 2012 6:04 AM
8	I havn't encountered any obstacles because the parents are given the referral to reach out on their own.	Dec 6, 2012 1:39 PM
9	Dificult to find direct phone number to connect with live person to answer questions	Dec 6, 2012 1:29 PM
10	Not applicable.	Dec 6, 2012 11:26 AM

Page 9, Q9. Are the families that you have referred to Children's Specialized pleased with the services received? Please describe below.		
1	For the most part yes. Some did question the effectiveness of the therapies offered.	Dec 17, 2012 7:35 AM
2	(NA)	Dec 10, 2012 2:01 PM
3	I only have one student, and he family is pleased	Dec 10, 2012 5:39 AM
4	I think the families are pleased with the staff and services. There have been occasions when a parent comes back to us with a prescription for a Section 504 plan, but that is for the school's Section 504 committee to determine, not for a doctor to automatically prescribe...If it is recommended, then recommended accomodations that should be in the plan should also be given. (Sorry, this probably should have been under the previous question about obstacles I've encountered.)	Dec 7, 2012 10:13 AM
5	N/A	Dec 7, 2012 8:24 AM
6	yes	Dec 7, 2012 7:46 AM
7	NA	Dec 7, 2012 6:04 AM
8	Yes, I generally get positive feedback after families go to CSH.	Dec 6, 2012 1:40 PM
9	Combination of pleased and cautious about recommending	Dec 6, 2012 1:30 PM
10	Not applicable.	Dec 6, 2012 11:26 AM

Page 10, Q10. Please share, if applicable, any new services or programs that you would like Children's Specialized to offer to better meet the needs of your students.		
1	Therapies that would incorporate high interest level activities for high school students.	Dec 17, 2012 7:36 AM
2	N/A	Dec 10, 2012 2:01 PM
3	Early intervention parents need a place to go to get braces and adaptive equipment as it is very hard to get vendors to come to the house. We could also use a local orthopedist besides the one from DuPont, where families could get seen and get xrays when they have limited transportation. EI families also need help with feeding issues in this area.	Dec 10, 2012 5:41 AM
4	I am in a desperate search for more services, programs, therapists who specialize in anxiety disorders.	Dec 7, 2012 10:14 AM
5	N/A	Dec 7, 2012 8:24 AM
6	more groups for tweens. More support for dx: of anxiety	Dec 7, 2012 7:47 AM
7	Social Skills groups; therapeutic nursery program	Dec 7, 2012 6:05 AM
8	None	Dec 6, 2012 1:40 PM
9	Clearer understanding of services in new facility in Egg Harbor Twp More evening hours for working parents	Dec 6, 2012 1:31 PM
10	I have very limited knowledge of services or programs that Children's Specialized offers to students.	Dec 6, 2012 11:27 AM

Page 11, Q11. Please share any specific programs and/or services that FAMILIES you have referred would like Children's Specialized to offer.		
1	None	Dec 17, 2012 7:37 AM
2	(N/A)	Dec 10, 2012 2:01 PM
3	see previous answer	Dec 10, 2012 5:42 AM
4	I am speculating, but probably services dealing with anxiety issuesand help with executive functioning/ADHD issues.	Dec 7, 2012 10:15 AM
5	N/A	Dec 7, 2012 8:24 AM
6	groups	Dec 7, 2012 7:47 AM
7	social skills groups, parents workshops, therapeutic nursery	Dec 7, 2012 6:05 AM
8	None	Dec 6, 2012 1:41 PM
9	Social skills group in southern Ocean County or nearby Any summer programming that is affordable or has grants for needy families	Dec 6, 2012 1:32 PM
10	Because I have limited knowledge of programs offered by Children's Specialized, I have not referred any families.	Dec 6, 2012 11:28 AM

Page 13, Q13. Please share anything specific Children's Specialized Hospital should be doing to better support you in meeting the needs of your students.		
1	Same as previous question about high interest level activities for older adolescents.	Dec 17, 2012 7:38 AM
2	Meeting times are somewhat difficult to accomodate staff from CSH	Dec 10, 2012 2:02 PM
3	working together with primary therapists would be great- have not had much experience yet , but so far the out reach by your PT's is appreciated	Dec 10, 2012 5:43 AM
4	Perhaps requesting specific information and feedback from the school/teachers when doing an intake for a student to get the whole picture of the child, not just the parent report.	Dec 7, 2012 10:17 AM
5	None	Dec 7, 2012 8:24 AM
6	better understanding of the school environment prior to writing a list of school recommendations that are nearly impossible to implement	Dec 7, 2012 7:48 AM
7	workshops for parents	Dec 7, 2012 6:05 AM
8	I don't know how this can be resolved, but offering shorter waiting periods for appointments.	Dec 6, 2012 1:42 PM
9	With signed request from parent, District could receive reports directly Seeking teacher input regarding child's classroom behaviors and academic progress	Dec 6, 2012 1:34 PM
10	Is it possible to do mailings to school districts in order to learn about the programs offered by Children's Specialized Hospital? This information can then be used to inform parents of the programs.	

APPENDIX D

Children's Specialized Hospital
Focus Group Meeting
August 21, 2012
Parents Focus Group

IV. Overview of Needs Assessment/Purpose of Focus Group

V. Questions

- How did you learn about Children's Specialized Hospital?
- Are there obstacles that you encountered when attempting to receive the services of CSH? What would have made the process easier?
- When you think of Children's Specialized Hospital, what would you want to see done differently, what services should be added and what has not been as much value to you in terms of their offerings?
- Do you think Children's Specialized and all of its services and locations are well known? If not, how might the hospital educate or raise awareness of its offerings.

VI. Next Steps In the Process– Conclude the Meeting

APPENDIX E

Children's Specialized Hospital
Focus Group Meeting
August 21, 2012
Hamilton Site
Parents Focus Group

Ms. Sellers provided a brief presentation regarding the process involved with a Community Health Needs Assessment followed by questions posed to parents. The focus group responded as follows:

How did you learn about Children's Specialized Hospital?

- From pediatrician. Son had speech delay, evaluation done. Called others to check their experiences with CSH. Positive experiences.
- PT came to home and did eval. PT said that CSH took our insurance.
- Lived in Ohio, then moved to NJ. We were admitted to acute care hospital and then social worker told us about CSH.
- Hamilton location was newly built. I was in a mom's group and a mom told me about CSH. I contacted EIP and was put on waiting list. I became an advocate and now I tell everyone I know about CSH.
- Friend of mine works for CSH. I believed there were better services provided by CSH and a better reputation.
- Solicited by Director of Admissions while we were in critical care.
- Worked at nursing home next door to CSH facility. I adopted a special needs child and now have been working for CSH on and off for 20 years.
- Orthopedic eval done by CSH doctor – referred to this doctor by my pediatrician.
- Daughter was part of Lightning Wheels. She became very sick and went into acute care. Based on exposure to organization I knew I would be going to CSH.
- Initial pediatrician said that it wasn't bad and that they will come along. Another mother said I should get a second opinion and I paid for private evaluations. Then I looked at insurance and got on the waitlist for CSH. I wanted doctors who were willing to work with me. I always suggest CSH – will take our insurance. A lot of parents don't know this.

- Pediatrician caught language delay (Westfield). Referred to CSH. EIP person was from CSH and school system also knew about CSH.

- Daughter was at Robert Wood – they referred us.

- Through social worker at acute care hospital and have now been involved over 18 years.

What obstacles have you encountered?

- 8 month wait

- 8 month wait also

- Varied experience. Initially seen right away. Speech services took 6 months.

- Experienced angst with the waiting

- Personal family issues. When they reach their goals, what's next. School scheduling issues.

- I have two children who need services. Getting both scheduled for sessions next to each other. Schools say that they offer services and that we don't need to go outside. Had to work system and convince them that they needed therapies outside to be able to excel in school. Was told "that's medical based, this is academics based" and "we're not accepting those evaluations".

- I had to get 3 evaluations for my school.

- I wish someone could bridge/advocate for families in their relationship with the school systems. Currently parent is forced to take on this expertise to bridge the gap – and we don't have the expertise.

- I almost left CSH. It was not a good match with the first neuro doctor. Could only switch doctors if got chairperson's approval. It took three days to reach this person. Frustrating experience.

- We lost our OT, PT and Neuro development doctor. They relocated and now I can't access them.

- Had to wait a month for therapy to begin after discharged from Inpatient (IP).

- Government/Medicaid involved complicates things much more now. It was a smooth process 18 years ago.

- Transition from pediatric to adult care. There needs to be a better transition process. One year into adult and they still don't know who we are – we're just a number. We don't feel like we are partners now – like we did at CSH. The adult providers do not understand the pediatric perspective. There is not as much Hope in the approach. I wish there was more education from pediatric to adult providers.

- Need for increased communication between therapists in different specialties – a more coordinated, holistic approach.

- Better communication from scheduling staff when there are issues

- I have seen improvement among care team

- Still need improvement in holistic approach and the communication needed

- Parents have to really push for coordination and have speech work with OT for releases, for example.

- Not everyone knows the case specifics and plan for patient – issues not clearly communicated.

- Recently on a call – told 3 minute wait, then switched to wrong site and told another 4 minutes. Ended up waiting 17 minutes – frustrating.

Any services you would like to see that are not currently offered?

- As needs change – looking for out-of-box thinking. Switched to therapist that wasn't working – took 7 months to get it changed. Lack of ability to look at smaller or more detailed things – using "hey dude" instead of just "hi" for the child to effectively communicate to his/her peers at a certain age. Expanding to a different level in providing service. Not just a set cafeteria experience – going beyond norm.

- Ideally, for kids getting into more fine motor skills – extracurricular/group therapy to get to next level. Goals are met – but there could be more goals.

- Get past "hi" to "hey dude".

- Balance needs/desires for current patients with the wait lists of kids waiting for services.

- In best of worlds – parent concerns and worries about other children and the entire family would be addressed. My psychological needs to be addressed also. Perhaps a fee-based service provided for parents and addressing what they need.

- There was a parents group with a social worker when I first came. Would like to have a parents group facilitated by CSH.

- Some therapists at CSH actually include whole family in the conversations. This practice needs to be spread throughout the organization.

- There are not many social workers who serve the outpatient population. Wish there were more of these services on the outpatient side.

- Insurance and how it works. Someone who can explain where other resources may be in the community. An internal advisor around financial realities we are dealing with.

- All of my needs were met in IP for 9 months and as outpatient (OP) for over 3 years. Haven't had a bad experience. As an IP the therapy team would huddle every morning and communicate with each other to make sure everyone knew what was going on. And even members who were not on the direct team would offer ideas to try. At Tom's River they still communicate OK, but on a more informal basis. I was shocked at how well everyone communicated with each other. I was appropriately "bugged" to make sure I was communicating with everyone also. I know one family who drives an hour and a half each way to receive a specialty therapy treatment related to lung cancer. They wouldn't go anywhere else.

- A need to look at entire family – especially in LTC. Many families have many long term issues. It would be great if there were a psychologist available. The one social worker is spread thin and is split between IP and OP.

- Especially help with siblings as part of the holistic family needs

- Links with other families with similar experiences/diagnoses/conditions.

- Everything in one place. It would be great to have a pediatrician at the same site. I don't trust my pediatrician – would like to have a pediatrician associated with CSH.

- Language barriers for Latino population. Need a real person, not just telephone interpretation service. Need for more bilingual staff.

- No problems with LTC. They address all of his needs. All the newest stuff/approaches are going to happen at CSH.

- I like that CSH has family faculty. They need to play this up more. Ongoing parent networking.

- I didn't know about family faculty until after we were discharged. I also didn't know about Parents Advisory Council until I overheard someone talking about it.

- Transitions when therapists are changed could be better handled. Sometimes we didn't know until we arrived for session. If knew in advance we could prepare and make session more valuable.

- More support groups for parents. Connecting parents to be resources for each other.

- Support groups and activities for kids as they grow older. Can't wait for Friday Night Fever which starts at age 13.

- Pediatrician not on board. CSH can provide connections and education for pediatricians, dentists and other providers in the community – and school systems, creating alliances. Need language appropriate for school systems.

- No one knows about CSH in my area (southern part of the state?). I say Children's Specialized and they say "who?"

APPENDIX F

Children's Specialized Hospital
Survey of Inpatient and Outpatient Referring Clinicians

CSH's Director of Referral Development/Admissions provided a cross section of inpatient (IP) and outpatient (OP) referral sources with representation from different geographic regions in the state of New Jersey. Letters were sent to 32 IP referral clinicians and 37 OP referral clinicians. The IP referral sources included physicians, nurses, a nurse practitioner and a social worker. The OP referral sources were all physicians.

Out of the total of 69 letters sent out, 16 surveys were completed as follows:

Inpatient referral sources	
Social Worker	3
RN	3
Physician	2
Unknown	3

Outpatient referral sources	
Physicians	4
Anonymous	1

Have you worked (referred patient) with CSH in the past?

Of the 16 responses, 14 responded "yes" and 2 responded "no."

If no, are you familiar with CSH facilities, its services and programs?

Of the 16 responses, 11 were very familiar, 4 somewhat familiar and 1 not familiar

- *"Have referred patients and am very familiar."*
- *"I am very familiar with Children's services and facilities and have made referrals numerous times.*

When working with Children's Specialized, have you been pleased with the services and support provided by the staff?

Of the 16 responses, 12 were very pleased and 2 somewhat pleased

- *"Very pleased with Admissions Director & Coordinators. Have received complaints from former patients about nursing."*

- *"Morristown Medical Center has a very good relationship with the admissions staff at Children's Specialized Hosp. The CSH Admissions staff is always responsive & helpful regarding referral for our hospital."*

- *"I have been pleased with the Referral Staff. Sharon D'Antonio is fantastic and responsive. I have not been pleased on a few occasions with the reports and the quality of the care that we hear from our referred patients. I called the Nursing Manager that evening and she did not seem very interested in approaching the family or fixing the issues."*

- *"Admission procedure is fantastic."*

- *"Staff is excellent, care is excellent. No similar svcs in NJ."*

- *"Barbara Marrone has been wonderful as a nurse liaison between our facility and Children's. My only request would be that the financial dept. at Children's be able to offer more assistance in obtaining authorization for transfer to Children's." I am a social worker who covers a 55-bed NICU; the time it takes to obtain auth. Takes away from svcs. I could be providing to their families. Any assistance the financial dept. at Children's could provide would be beneficial."*

- *"Sharon D'Antonio is a pleasure to work with."*

- *"The employees at CSH are very helpful w/doing a referral. Sharon D'Antonio is very helpful."*

What obstacles, if any, have you encountered when reaching out to Children's Specialized on behalf of your patients?

- "Some limitations of care that can be provided in rehab setting necessitating a longer hospital stay when rehab more appropriate. Limited rehab services on weekends and inability to tsf on weekends unlike most of adult rehabs.

- "None"

- "Obtaining authorization from insurance. Although CSH has a finance dept., and I hear from insurance companies all the time that they need to speak with them, I feel that all the ownership is placed on the transferring hospital to obtain auth."

- "Referrals and responsiveness are not a problem. The issue may be regarding care delivery."

- "Only the distance."
- "No significant obstacles from Children's, however, some insurance carriers make referral difficult."
- "None"
- "Availability of appointments or inpatient beds."
- "No obstacles; Barbara Marrone has a quick response time, and if she is not available, Jeanne Brooks & Sharon D'Antonio are more than helpful."
- "None."
- "I have never encountered any obstacles; their admissions dept. is very accommodating both to our institution and to our families."
- "None"
- "Generally no obstacles related to children's specialized side."
- "At one time CSH did not provide transportation for the PT parents. This resulted in less referrals from us because the parents had no way to get there even with the offer of bus passes & train passes."
- "Not near patient base."

Have your patients had to wait for a period of time to work with Children's Specialized?

Of the 16 responses, seven indicated they had to wait while another seven reported no wait and two indicated not applicable.

If yes, please describe:

- "Especially for outpatient referrals."
- "Admissions staff is very responsive for our acute inpatient rehab patients and beds have been available as needed. As discussed before, the situation is very different for long-term placement at Mountainside and more beds are necessary to meet need."

- "Due sometimes to bed availability, sometimes to medical clearance on our side."

- "….. it is not usually too much of a problem."

- "Had two occasions where there were no beds available.

- "Occasionally we have to wait days to weeks for an inpatient but when it is an emergency it has always worked out. Scheduling of outpatient services can be challenging."

- "Bed availability is sometimes tight."

Please share, if applicable, any new services and/or programs that you would like Children's Specialized to offer to better meet the needs of your patients.

- "Increased information sharing possibly in the form an EMR or chart for transfers back to the hospital from both the acute and long term care areas. Transport services back to CSH after hospitalization for long term care patients as Logisticare refuses to transport an unaccompanied minor. This often times delays tsf until a family member can be available. Ability to transfer patients back to long term care on weekends."

- "Further development of a comprehensive adolescent in-patient Chronic Illness Program which would include family therapy, psychiatry, plus medical/rehab/education with a transition piece and follow-up on discharge. This could be modeled on Cumberland Hospital for Children and Adolescents n New Kent, Virginia. It is a hardship for children and families to have to travel so far from New Jersey for this service and transition and linkage into community services afterwards is problematic. New York State families could also benefit from having this service nearby and provide a further source of referral."

- "None."

- "None."

- "PICC line/port a cath care; we also had been told that we would be receiving frequent status and progress updates, that has not occurred.

- "They have a great program overall and we're happy to have you for our patients and families."

- "None."

- "None."

- "Nothing in particular comes to mind other than accepting cognitively impaired young adults who are greater than 18 years of age."

- "None that I can think of at the moment. The neonatal abstinence program has been a wonde4r program that has served several of our families."

- "Adding transportation for families was a huge gift for our families. Waiting for a DVD that we can play for the families to introduce them to the facility & the available services."

- "I find Children's services to be very complete."

- "None."

- "I mostly use the feeding program. I was wondering if CSH would also supply transportation to out-patient services such as these. Also PT and OT."

- "Not sure what is available."

Are the families you have referred to Children's Specialized pleased with the services received? Please describe below:

- "Not always. Most complaints center around nursing services not rehab services."

- "For the most part families are very satisfied. Some parents have commented that they felt nursing could be better i.e., more available and/or responsive, especially on weekends (New Brunswick location). I have also heard complaints about nursing in the long term care unit that not enough attention was being paid to the patients."

- "N/A."

- "on the whole, very pleased, although they would prefer to stay within the same age range."

- "…it has honestly been a mixed picture. Some families are pleased and some are incredibly disappointed or angry with the services—it is hard for someone off-site to really gauge the quality based on patient feedback."

- "Usually very!"

- "Yes, very pleased. I have received no complaints."

- "No feedback."
- "Families have overall been very happy. Only concern has been from more medically complicated patients who are concerned that medical problems seem to stress out staff/nurses."
- "Feedback that I have received has been positive."
- "Yes, we have not had any complaints."
- "Absolutely."
- "Yes."
- "Some families are very pleased with their inpatient stay. Some families felt that therapy was not aggressive enough."
- "N/A"

Please share any specific programs and/or services the families you have referred would like Children's Specialized to offer.

- "It is the access to service that is most requested."
- "As described before."
- "N/A"
- "I have had no specific feedback related to additional needs in this area."
- "None that I can think of at this time."
- "Maybe some financial assistance for the very complicated babies."
- "None."
- "None."
- "More comprehensive neuro-cognitive follow-up."

- "Not aware of any."

- "The transportation was the only barrier to referrals and that has been removed. Otherwise the parents have not mentioned anything lacking."

- "I can think of no additional programs or services."

- "Neurodevelopment program."

- "I think a Ronald McDonald House would be very helpful so parents can stay as long as they want. I am aware that the parents are allowed to stay, but it would be nice to have a place to go to."

- "N/A"

How well-know do you believe Children's Specialized and the services it offers are in your community?

Of the 14 responding:

4 indicated "Very Well Known"
5 indicated "Somewhat Known"
3 indicated "Name Familiar But Not Services"
2 indicated "Not Well Known"

- "The average family and potential referring physician have no idea re: the breadth of services offered."

If known within the healthcare community, how would you describe the reputation of CSH?

- "Generally well regarded, the Kessler for little people."

- "I believe CSH enjoys an excellent reputation with those I the healthcare community who know the facility and its programs. At times I have heard concerns from the medical staff that patients from CSH Long Term Care could possibly have been transferred earlier for in-patient hospitalization thus shortening hospital/PICU stay."

- "Well regarded."

- "It is good, it is also the only one of its kind in the area, which helps."
- "Among referring physicians it is well regarded. Families at first are unfamiliar with the institution, and further opinions are based on care received."
- "Excellent."
- "Very good."
- "Good."
- "Top- notch. It has a great reputation for highest quality rehab services."
- Outstanding rehab and long term care. Motivated to get children back home with their families and to teach family members how to best are for their children."
- "Respected for the work they do, only issue remaining is ability to transport patients they are ready to go. Bed capacity remains an issue."
- "Excellent reputation."
- "Very reputable and good and timely feedback to the primary physician."
- "Very few of the families I have spoken to know about CSH."
- "N/A"

Please share anything Children's Specialized Hospital should be doing to better support you in meeting the needs of your patients?

- "Progress reports for referrals that can be shared with the referring physicians and specialists to better anticipate discharge needs following rehab."
- "Continue to provide excellent service…."
- "Publicize the served offered in my community (Clifton)."
- The rep we work with is very accessible, she is knowledgeable about the children's medical conditions and what will transfer to therapies. The insurance is the biggest barrier if there was less of a stigma about taking kids later in the day it would be helpful."

- "Further status updated regarding referred patient progress, discharge planning, etc. Often times the ICU physicians and staff who worked so hard to resuscitate and stabilize these patients have no further communication and lack updates regarding the outcomes of their patients."

- "Assistance with the transition into the community."

- "Overall I'm pretty satisfied with the level of service both to my patients and to my staff."

- "I would appreciate receiving discharge summaries for the patients the trauma service refers to CSH."

- "Better coordination with pre-certification of procedures."

- "Cannot think of any at this time."

- "Improve bed capacity in both facilitates, acute rehab & long term care."

- "I can think of no other services or programs CS should offer to meet the needs of our pts/families."

- "Keep the primary physician well informed on the progress of the patient in all the aspects of the treatments & prognosis of the disease."

- "Parent just want easy access. I think providing transportation was very good."

APPENDIX G

Phil Salerno III
President and CEO
Children's Specialized Hospital Foundation

What is your role within CSH?

I've been at Children's Specialized Hospital (CSH) for 25 years. Lot of things have changed over time. Rich ran the hospital as co-president with Dr. Zarafu and then Rex came in from California to run CSH and was there almost three years. And then Amy Mansue came in 9 years ago.

What changes have you seen occur over the years?

Changed a lot in the sense of growing from Mountainside to Fanwood to Toms River and now have 10 sites around the state. Instead of treating 2,000-4,000 kids a year treating 20,000 kids a year. Foundation Board is much stronger. Even as recently as ten years ago we had good corporate relationships and now have eight to ten really strong corporate relationships with six figure donors. PSE&G is completing their ten year commitment of five million dollars. In the worst of the economy last year, CSH still raised six million dollars. Performance stayed level but did not crash and now things are improving. I'm not sure if hurricane will impact donors in November and December. We are running ahead of budget by $900,000 of where we were in 2011.

CSH has been able to serve a much larger community. As our profile has been raised, awareness has been raised throughout the state. Now companies coming to CSH to get involved. We changed the position of director of volunteer services to director of community engagement. We will probably have 20 or more companies come in to volunteer. These things were not happening ten years ago and, as a result, more people know about CSH; there is an increase awareness and number of people served.

Have ten outpatient sites around the state. Every time we open an outpatient site it becomes profitable within 18 months. In 2001 the Board decided to create a presence in New Brunswick. People have a positive experience in any of the sites and talk to their friends.

What barriers or challenges does CSH face?

The greater we can broaden awareness, then people will turn to CSH. If you have a child with autism, you might not know that we do attention defici. Acute care hospitals may say they have these services but they really don't. In her role as CEO of a Children's hospital, Amy has made a huge difference. In a lot of ways we are trying to raise awareness with the community involvement piece. Marketing was moved to the Foundation. Now we just need to get the word out. We can't compete with the larger hospitals' marketing budget. What we spend in a year most will use for one campaign.

One of the things we are bad at doing is celebrating the things we do. Amy brought Dave Knowlton in and he said our outcomes are the best they can be but no one knows that and he said it should be touted. When we do things and something great happens, we don't raise it to the level of newsworthy. On a bigger picture we need to acknowledge and publicize the great things that we do.

We need more people in leadership positions involved on other boards to hear what others are thinking especially if they are not in the healthcare realm.

Jennifer Jacobs
Vice President, Government Relations
Amerigroup New Jersey

What is your role at Amerigroup?
VP of Government Relations.

How do you interact with Children's Specialized Hospital?
I know Amy very well. We have a relationship from a policy perspective. My primary interaction is with Amy. Members need her facilities so certainly my company has a relationship beyond government realtions.

Have you seen a change in the demographics as they relate to children with special needs?
Don't know.

Have there been changes in relation to the types of services needed by children with special needs?
We have had a significant change in the last year because Medicaid programs moved the medical day care benefit into the health plans. Before, when a child was using her medical day program the State would have paid for that directly. As of 7/1/11, that benefit came under managed care. That was a significant change. Going forward, next July health plans will begin to pay for long term care.

What are the challenges in covering the cost associated with children with special needs?
The State has a rate for medical day care and when they moved the benefit over just to avoid any kind of unnecessary bumps in the road, the health plans adopted the state's rate. However, the state cut health plan rates last year. Medical costs go up every year based on inflation alone as well as technology costs, etc.. Rather than increasing the rates, the State decreased the health plan rates and that put extra pressure on the Plans. One Plan decided to cut the rates and there was a firestorm and providers went crazy. Another health plan that was going to cut rates (largest in state). They said "if we get cut, then you get cut." That firestorm is still out there. That Plan has not actually cut the rate yet but that is their intention. Rates are already too low and some facilities were not being paid enough. Acute care, drugs, and specialty care are going up so if the State doesn't increase rates, then there is pressure all the way around. If you are paying based on acuity of the patients, then CSH might win because of the acuity of their children. That might be a valid argument for CSH. Cost pressure on the health plan side is that the State is under a lot of pressure and it is cutting the rates to the plans. Acute care hospitals are very powerful organizations; when the budget gets tight, the hospitals are still pushing their weight around.

What could be done differently, if anything, with the relationship among the providers, the health plan, and the parents?
One of the things that we talked about is that there are certain provider types, medical day care and home care; they are seeing our members every day and there may be information they have that would be helpful to Amerigroup (AG). AG, in turn, might have info that is helpful to the provider. For

example, AG is judged on how they perform on preventive care for children. We are tracked very closely. If medical day programs knows that AG is missing vaccine or hasn't had a well-visit or is a diabetic, then the medical day care could help ensure those services are being provided. AG would benefit because they would improve their scores and the families would benefit because their children are getting preventive care.

HEDIS is used to score health plan performance as well as CAPPS which is a satisfaction survey. If we could coordinate to get better results, it pays off all the way around. The family has a healthier kid, the provider gets revenue and the health plan improves their score. Quality is always on AG's mind as they have to demonstrate improved outcomes.

In your opinion and given those you insure, are there sufficient services and/or sites of service to meet the children's' special needs?

I can tell you for sure that special needs dental is a problem everywhere. We transport members all over the state trying to get them to a special needs dentist. There is a fantastic special needs dentist in Old Bridge, Dr. Brunsden. He is very creative and works within the community. If there were partnerships that would increase access to dental for special needs kids that would be huge.

AG does not cover mental health. Their mental health network is not well run by the State. It is crisis oriented not preventive. There is already a significant problem. The State is willing to contract out the services themselves rather than allowing the health plans to have a subcontractor. They will subcontract with Magellan. The new long-term care piece is coming next July, those folks will be covered by mental health under AG. Spring of 2013 or sooner we will look to recruit mental health providers for long-term care and also for pediatric. There is a scarcity of these professionals. Because there is no infrastructure for mental health, AG has to go out and develop a network and find the professionals.

John Crisan
Chief Compliance Officer
Johnson & Johnson International, Inc.
Member, CSH Board of Trustees
Secretary, CSH Foundation Board of Trustees

What is your role?

I am the Chief Compliance Officer for Johnson & Johnson (J&J). Up until nine months ago, I was general counsel for consumer business at J&J. I've been sitting on the Board of Trustees for CSH for several years now and I am Secretary of the Board for the Foundation. The Foundation is separate from the hospital. Its primary purpose is to help fund the hospital.
Although I'm based in New Brunswick, I live a couple of blocks away from Mountainside Hospital.

How do you interact with Children's Specialized Hospital?

The day-to-day operations are not heavy duty. Most interaction is with management team of the Foundation and also knowing of the hospital by interactions with Amy & Warren and the more senior people at the hospital. Mostly that is from presentations to the Board. I participate in strategic planning and development. My son volunteered at the hospital when he was a teenager. I would periodically help familiarize other people as to the hospital's mission and objectives. My primary purpose is to help guide the Foundation which is the money raising arm vs. day-to-day operations of the hospital itself. J&J requires charitable contributions that impact the communities in which they are located.

Changes/Evolution?

Since I joined six years back I will say that there has been tremendous growth in the population CSH serves in terms of additional facilities and satellite facilities around the state. CSH continues broadening the reach of the hospital and it does seem to be driven primarily by the needs of the population base. Where there are not strong service providers, CSH is able to reach more patients that need their services.

Amy and their former Chief Medical Officer have done an outstanding job leading the hospital from a relatively small footprint and obscurity to a larger footprint and broadening its reach. The organization is doing continuously great things with high caliber people. I'm not sure the Foundation piece has become as sophisticated or grown as much as it should have given the growth at CSH. Look at where CSH is today compared to six or seven years ago and look at the Foundation arm, it is almost where it was six or seven years ago.

What Should Change?

One area they are already looking at pretty comprehensively is the geographical expansion. I wouldn't say they should do more as I think it is already ongoing and probably needs to continue. They don't control whether they should be looking at some sort of transformational relationship with RWJUH. There is consolidation in healthcare industry. How do we as a specialty hospital accomplish something appropriate along those lines recognizing affiliation with RWJUH? Staying ahead of that curve is critical.

I think the Foundation could and should do better. It is doing ok and it has made progress but my view is that it is still a little bit of a work in progress. It needs to almost move to the next level in terms of sophistication and in size. It has been relatively flat in terms of the dollar amount and, as the hospital gets bigger and has more commitment to patients, so is the need for more money.

Leadership is CSH's greatest strength. Between Frank & Amy, that was a driving factor in terms of their growth and their success. They were able to set the right culture although it was there before with Frank. They've strengthened the culture. They have great people and need ongoing great leadership.

CSH has a niche. It doesn't have a lot of significant competition that can match it in terms of what it provides. Focus is on a niche area while other hospitals have this as a side service. They can't match the quality and focus of CSH because it's not a niche for the hospitals. Being a niche, however, may actually hinder ongoing growth. Medicaid gets reimbursed at rates that are grossly inadequate because they are designed for long-term care because they don't fit neatly into a reimbursement line—CSH is treated as a long-term care facility and they aren't.

Another area to look at or change is succession planning: Frank is gone and he was a great leader. I am concerned that Amy may leave and take on another role and not to diminish her management team but, particularly in this very rapidly changing healthcare environment, having greater comfort in the succession planning to backfill those roles is critical. The other thing I would say is that the Foundation has had a high amount of turnover so there is some work that needs to be paid attention to. How people are managed and the expectations that are put upon the people in the Foundation needs to be examined and addressed. Given the environment it may be harder attract and retain the right people.

I want to ensure I see the final report. Trustees need to know what is going on with the hospital so this would be helpful in sharing this with the Foundation.

Pat Foley, Associate Vice President
Outpatient Services
Children's Specialized Hospital

What is your specific role at CSH?
I oversee all of outpatient services which include outpatient therapy, oversight of outpatient sites, and also the administrative responsibilities of the ambulatory care facilities. I've been here twenty years.

How have you seen it evolve over the last five years?
First thing would be leadership and the transparency of the organization. Growth has been huge. Insurance and managed care have changed and affected our parents. There is a wider variety of patients and their diagnoses and parents expectations of us are much greater; not just clinically but the whole package, like how long it takes to get an appointment, where they get an appointment, etc.

What areas do you believe could be further developed?

For Parents: I think that we could offer more support or support groups for parents. I'm not sure it is our primary role but if we had other resources to give them, then it would help. There are not a lot of resources or support groups for them out there.

For Patients: Because of where we came from, we used to see very involved children. Sometimes we missed children with milder conditions. For example, we offer sports medicine but people only remember what we were before (treating children that are severely disabled) so they don't think to come to us. It's different at outpatient sites because it is not a hospital. If a child had an orthopedic injury they wouldn't think of CSH but awareness could be developed. Parents and their kids don't make their way to you because of a lack of awareness of preconceived ideas about CSH. Parent will say, "Oh my god, I didn't know you did this."
I think it would be nice to have more community resources for them.

Are there services you think are no longer needed?
I don't think so.

Do you think most healthcare and educational providers are familiar with CHS within their communities?
Providers: If they've sent children to us, then yes. It is something we can expand on.

Educators: Less so than providers. If they refer here for services they think they will be responsible for providing it. If it's educational then they'll refer to CSH and then the parents think the school should be providing and the parents shouldn't have to pay. They are less inclined to send a child if the school district has to pay or if the parent has to pay but what tends to happen is CSH tells them what the children need and then they ask the school district to get it.

If not, what could be done to address this lack of awareness?

Providers/Pediatricians: Just getting out there and letting them know what we do. When we do it, it opens their eyes to the various services.

Educators: I think again it's a delicate balance. They don't have the conversation because they think they will then have to offer the services and may not have funding to do so.

What do believe are the top three or so priorities in terms of meeting the needs of your patients and their families?

- Expansion and growth – We have to cover more of New Jersey. We need to be geographically dispersed to provide greater access.

- Continue to be able to have the quality staff and number of staff to provide the excellent services. It is a challenge especially with physicians. We have the largest number of neuro-pediatricians. There are so few coming out of medical school so there are not many to draw from. Even from OT/PT, we are a specialty area so there aren't enough that have that specialty training especially throughout the state.

- If we could give kids access to our care, that's great. Being able to provide them with resources in the community helping them to transition to the community. Not all kids need to stay with us forever. They may need resources like study habits and learning or physical resources like gyms where kids could go to work out or fitness classes for children with special needs. I would attribute the lack of these services to numbers that aren't significant and the fact that there isn't a lot of money in it. There are some counties that have amazing programs like Monmouth County. Toms River has a challenger's sports league. Hard to say to a parent that you don't need physical therapy anymore but there is still a need to keep physical just not at a skilled level. If Medicaid covered these programs, like gym memberships, then it wouldn't have to pay CSH.