



THE HSC HEALTH CARE SYSTEM
The HSC Pediatric Center

Caring. Serving. Empowering.

**Community Health Needs Assessment
2015 -2017
Full Version**

Prepared by
The HSC Health Care System
2015

The HSC Pediatric Center's Board of Directors approved the Full Community Health Needs Assessment for 2015-2017.

An executive summary version and an abstract with foreword are available at
www.hschealth.org/foundation/publications.

2015 -2017 CHNA Abstract

The Patient Protection and Affordable Care Act (Pub. L. No. 111-148) was enacted March 23, 2010. Section 9007 of that Act includes a specific tax-exemption requirement for non-profit hospital facilities to conduct and implement a Community Health Needs Assessment (CHNA) once every three years. The first required CHNA must be completed by the end of the hospital facility's first tax year beginning after March 23, 2012, and is effective for three tax years. The CHNA must include a strategy to address certain unmet community health needs that were identified as part of the assessment.

The HSC Pediatric Center (HSC PC) and its affiliates have prepared this comprehensive health needs assessment in calendar year 2015 following preliminary guidelines published by the IRS as of June 9, 2015. We completed our first CHNA in 2012. HSC PC will use this report to guide future operations for the betterment of the populations we do and can serve. We have designed implementation strategies to improve health care access, health outcomes, or address other health related needs that are lacking for populations at social and medical risk due to income status.

The HSC PC is a specialty children's hospital that has served a medically complex, chronically affected population from the District of Columbia and suburban Virginia and Maryland for over 130 years. It is part of The HSC Health Care System (HSC), which consists of a Medicaid care coordination plan (HSCSN), a home health agency (HSC HC), and The HSC Foundation. The HSC Foundation actively addresses many of the traditionally unfunded needs of this predominately indigent population, specifically through its National Youth Transitions Center. For decades, HSC has partnered with local Medicaid agencies to properly address the ever changing needs of long-term medically high-risk children. HSC collaborates with many community organizations to provide a variety of needed services beyond hospital care for this population.

This CHNA received input from a broad base of health care experts and community members served by HSC PC including DC and Maryland public health agencies, and Health Services for Children with Special Needs, Inc. (HSCSN). Contacted local experts participated in both structured and informal interviews designed to identify unmet health and related social needs that impact positive health outcomes for this population. The CHNA also examined recent published literature and relevant data pertaining to community health needs assessment results.

Based on findings and recommendations from health experts and community members, HSC PC examined the following unmet community needs: (1) lack of adequate insurance coverage for medical services, (2) lack of specific clinical services to improve health outcomes, and (3) socio-economic barriers to effective health and related social services.

HSC PC will launch the following initiatives in 2016 to address identified unmet needs: (1) continue charity services for non-covered outpatient specific inpatient services, (2) open an *Advanced Care Center (ACC)* offering outpatient care focused on early intervention for children with autism and developmental delays, and (3) increase participation in local community partnerships to aid in the development of more effective care-coordination or wrap-around care models.

Foreword

The HSC Foundation is the parent corporation and management company for The HSC Health Care System, a nonprofit health care organization committed to serving families with complex health care needs and eliminating barriers to health services. The System combines the resources of a care coordination plan (Health Services for Children with Special Needs, Inc.), a pediatric specialty hospital (The HSC Pediatric Center), a home health agency (HSC Home Care, LLC), and parent foundation to offer a comprehensive approach to caring, serving and empowering people with disabilities.

The HSC Foundation Community Benefit Statement of Philosophy

The HSC Health Care System has a long tradition of implementing initiatives to improve access to services, strengthen families, and build collaboration within the special needs/disability community. This philosophy of collaboration is a “core-belief” in our approach over the past decades to expand community networks of nonprofit, government, corporate and charitable partners that share and pursue mutual goals to benefit the collective special needs/disability community. The HSC Health Care System and its network deploy a wide array of resources that range from charitable care to grants, direct services and indirect support.

The population at risk we serve includes children, adolescents and young adults. However, we recognize that success means attracting additional elements such as families, schools and other agencies. Effective community service efforts must achieve progress beyond the health care arena and include social, recreational, nutritional, transportation, and supportive advocacy needs. The HSC Health Care System’s wide scope of partners and services reflects this philosophy. We are highly involved in planning and implementation of transition programs that will enable young adults with disabilities to advance from school to work and dependence to independence.

In order to successfully execute our community benefit’s philosophy, The HSC Foundation established the National Youth Transitions Center, and has organized a network of partners listed on our website (www.hscfoundation.org). We also routinely work with governments on all levels and have specific working relationships with federal agencies in education and labor through our partnership collaborative.

The HSC Foundation annually provides a significant amount of grants and awards to individuals, and organizations in the disability community. We deeply believe community service requires more than money. We have offered and are especially committed to a variety of direct service programs, employee volunteer efforts, and regular community health promotion events.

In conclusion, we believe our community benefits/services must be organized in the form of a collective. Since health and health status is influenced by many non-health determinants, our philosophical belief is that families must be strengthened and enabled to support us in these endeavors. Community benefit services happen best by inclusion of many institutions and individuals and extends far beyond a financial framework to include quality services, volunteerism, direct charity and the human spirit.

2015 Community Health Needs Assessment (CHNA)

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I. Executive Summary

Mission and Vision

The HSC Pediatric Center (HSC PC) has provided specialty rehabilitative and transitional medical care to children for over 130 years. We treat infants, adolescents, and young adults with medically complex illnesses or chronic disabilities such as developmental delays, cerebral palsy, pervasive respiratory diseases, and brain damage. The hospital is guided by a family-centered philosophy to not only help youth with complex medical issues, but assist the entire family in understanding and living with the challenges ahead. It is our mission to provide the highest possible quality care and to improve both health outcomes and experiences for the populations we serve.

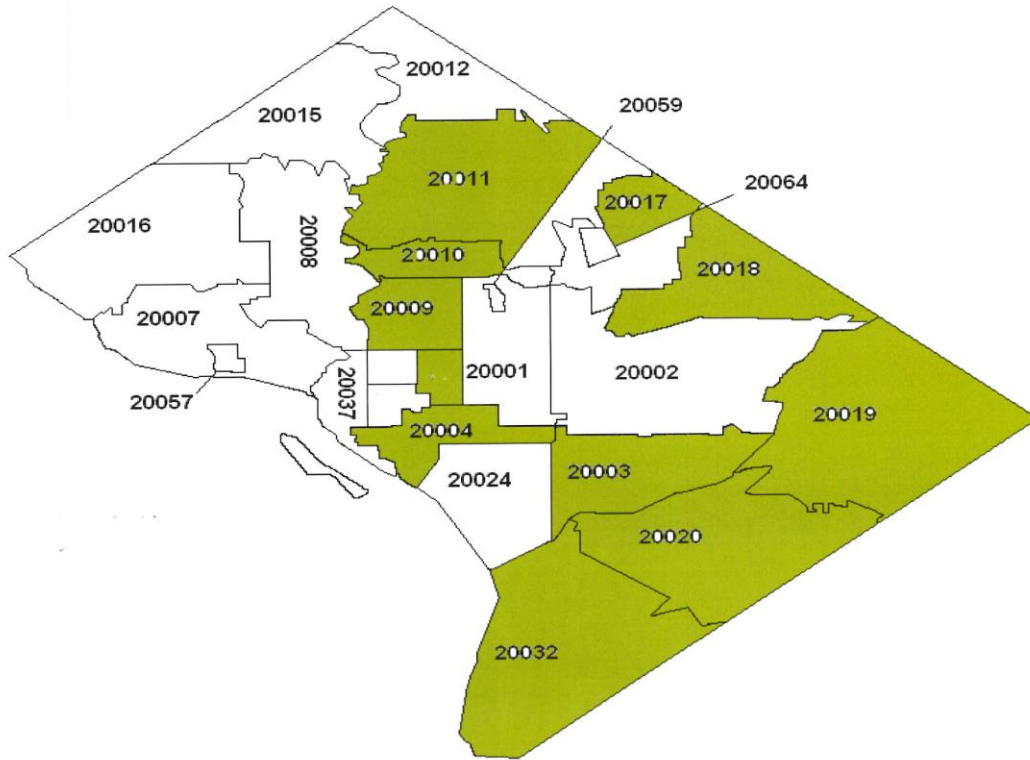
HSC PC's vision is to lead the region in producing or facilitating comprehensive, supportive, culturally competent, respectful, and high-quality health care services for children with ongoing special health care needs. We will continue active participation in projects with government, private, and philanthropic organizations both locally and nationally to help ensure unconditional access to services by all chronically disabled populations.

The Community We Serve: Demographic Characteristics and Unmet Needs Focus

HSC PC serves patients aged 0-21 with medically complex illnesses or with special health care needs within 50 miles of our northeast Washington, DC location. Based on 2014 HSC PC claims data, 54 percent of the patient population was from the District, while 14 percent and 31 percent were from suburban Virginia and Maryland respectively. The two maps below show both HSC PC's primary and secondary service areas in the District of Columbia and suburban Maryland.



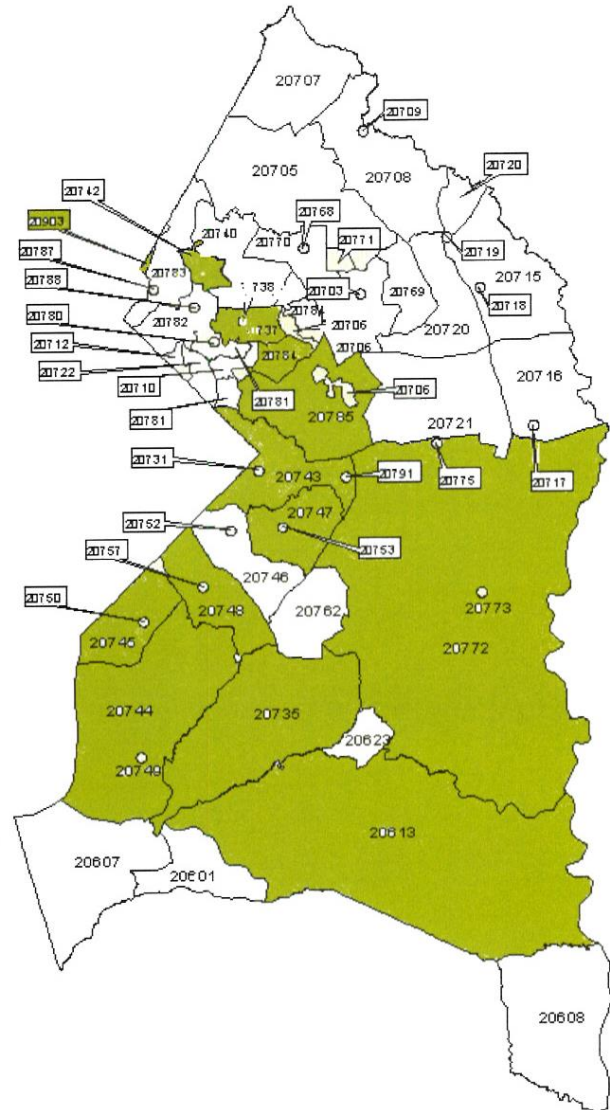
HSC PC Primary Service Areas – By Zip Code



* Predominant zip codes in Washington DC are highlighted representing 90% of HSC PC admissions

HSC PC Primary Service Areas – By Zip Code

- | | |
|----------------------------------|---------------------------------------|
| 20601 Waldorf | 20744 Fort Washington |
| 20607 Annapolis | 20746 Oxon Hill Area |
| 20608 Aquasco | 20746 Suitland Area |
| 20613 Brandywine | 20747 District Heights (Forestville) |
| 20623 Cheltenham | 20748 Temple Hills Area |
| 20703 Lanham-Seabrook | 20748 Fort Washington |
| 20705 Beltsville | 20750 Oxon Hill |
| 20706 Lanham | 20752 Suitland |
| 20707 Laurel | 20753 District Heights |
| 20708 Laurel (Montpelier Area) | 20757 Temple Hills |
| 20709 Laurel (Montpelier) | 20762 Washington (Andrews Afb) |
| 20710 Bladensburg | 20768 Greenbelt |
| 20712 Mount Rainier | 20769 Glenn Dale |
| 20715 Bowie (North) | 20770 Greenbelt Area |
| 20716 Bowie (South East) | 20771 Goddard Space Center |
| 20717 Bowie (Mitchellville) | 20772 Upper Marlboro Area |
| 20718 Bowie (Bowie Plaza) | 20773 Upper Marlboro |
| 20719 Bowie (West Bowie) | 20775 Upper Marlboro(Largo-Ketterin) |
| 20720 Bowie (South West) | 20780 Hyattsville |
| 20721 Bowie (Mitchellville Area) | 20781 Hyattsville Area |
| 20722 Brentwood | 20782 Hyattsville (West) |
| 20731 Capital Heights | 20783 Hyattsville (Adelphi) |
| 20735 Clinton | 20784 Hyattsville (Lanover Hills) |
| 20737 Riverdale | 20785 Hyattsville (Lanover) |
| 20738 Riverdale (Kenilworth) | 20787 Hyattsville (Langley Park) |
| 20740 College Park (North) | 20788 Hyattsville (Pr. Georges Plaza) |
| 20742 College Park | 20791 Hampton Park |
| 20743 Capitol Heights Area | 20903 Silver Spring |



This suburban Maryland map also highlights the predominant zip codes for HSC PC admits

The HSC PC provides both inpatient and outpatient services, which are primarily focused on medically complex pervasive conditions. Approximately 90 percent of the patients served by HSC PC are covered by Medicaid.

Table 1. HSC PC Inpatient Mix by Type of Admission, CY 2014

Hospital Patient Profile for Calendar Year 2014						
Hospital Service Groupings	#Admits ¹	Patient Days	ALOS	% DC Admits	% MD Admits	% VA Admits
Developmental-Long Stay	13	2,658	992	54%	23%	23%
Medical Extended Stay	28	3,101	205	25%	25%	50%
Medical	158	5,614	41	49%	39%	13%
NEW IV THERAPY	26	385	15	58%	31%	12%
Preemies	45	1,794	42	42%	44%	13%
Rehabilitation	37	570	21	24%	65%	11%
Total	307	14,122	92	44%	40%	16%

¹All patients admitted or already in house during 2014 are included.

Depicted above, the overall hospital length of stay in 2014 was 92 days. Inpatient stays at HSC PC include a hospital service group of patients identified as “developmental.” Developmental patients have more long-term, medically complex conditions and had an average length of stay of 992 days in 2014. For non-developmental patients, including a medical extended care group, the average length of stay was 205 days. Medical Extended Stay patients are more medically complex patients who require longer transitions.

Community Benefit Activities

Community benefits activities extend beyond the hospital, which has served an income challenged community with a variety of special health care needs for more than 130 years. The HSC Health Care System (HSC) as a system proactively provides community benefits to the populations we serve. It is part of our dedication to improving outcomes and experiences for individuals at risk due to disability, chronic illness, or other circumstances that present unique challenges due to income status. HSC consists of five (5) entities involved in mission-driven community benefits activities:

- A non-profit foundation, The HSC Foundation
- A carve-out specialty managed care plan, Health Services for Children with Special Needs (HSCSN)
- The National Youth Transition Center,
- HSC Home Care, LLC, and
- A specialty hospital, The HSC Pediatric Center

HSC as a system offers a very comprehensive approach to caring, serving, and empowering individuals with disabilities based on the following guiding principles:

- To work with government and private partners on all initiatives
- To select initiatives that address an identified service gap and that add value to existing work
- To bring additional funding (federal, corporate, foundation) to initiatives by serving as funding partners that have local impact and national relevance, and
- To support research and education, and advocacy that improves policies, programs and health conditions.

As detailed below, each entity actively supports various programs or activities to benefit the income challenged, disabled community.

The HSC Foundation (selected examples)

Since its inception, The HSC Foundation has supported a long list of activities and programs to benefit individuals of all ages with disabilities. Some of these activities involve significant financial contributions for relevant programs at HSC PC and HSCSN, that are not traditionally reimbursed, and other local or national initiatives focused on the unmet needs of the disability community in general.

The HSC Foundation continues to fund several local and national initiatives that support assistance to youth with disabilities and their families. The programs target gaps in funded, medical, social, or economic programs designed to benefit a special needs population. Below is a sample of The HSC Foundation economic programs designed to benefit the disability community. A full listing and more detailed information is available at www.hschealth.org/foundation/partners.

The HSC Foundation Grantees

- a. The George Washington University, – Graduate School of Education & Human Development. The [Heath Resource Center](#) serves as a national clearinghouse on postsecondary education and support services for individuals with disabilities. The HSC Foundation has partnered with the university to expand the content of this resource.
- b. The Washington Center for Internships and Academic Seminars. HSC funded expansion of its Civic Engagement Project around disability issues that helps students develop a greater understanding of the disability rights movement and current issues faced by the disability community.

Health Services for Children with Special Needs (HSCSN)


HSCSN was incorporated on February 2, 1994 as a demonstration project under a District of Columbia Health Care Financing Administration 1115 waiver. Today this ground-breaking managed care organization is currently serving more than 5,800 children and young adults in the District of Columbia's Medicaid Program who have Supplemental Security Income (SSI) or are SSI-eligible. As part of The HSC Health Care System, HSCSN offers a comprehensive managed care approach that promotes optimal health or adaptation to chronic conditions, improved life outcomes, and independence.

HSCSN also provides beneficial community activities that involve family and community support groups and activities to jointly identify and creatively remedy situations that threaten the optimal health of members, their families, and the disability or at-risk community at large. Through HSCSN, The HSC Foundation independently funds the activities below not covered under the District of Columbia managed care contract.

- a. **The Family and Community Development Center** provides a free, multi-purpose room and community trainings, meetings, child care facilities, family support activities, and a community resource center for families or individuals in the surrounding southeast DC.
- b. **Sponsorship and Participation in the Community Services Advisory Committee (CSAC).** CSAC is a committee of HSCSN adolescent members and their families who meets monthly with health care providers, advocacy groups, District of Columbia agencies, and other community representatives to improve outcomes through member self-advocacy,
- c. **Parent Advocate Leaders Support Group (PALS)** is a community based peer outreach program that provides advocacy training, peer support, and mentoring to HSCSN members and their families during monthly meetings with community partners.,
- d. **Male Caregivers Advocacy Support Groups (MCAS)**, which provides outreach, training opportunities, and empowerment to the male caregivers of HSCSN members as well as other children with special health care needs in the community. HSCSN works in collaboration with the Georgetown University Center for Child and Human Development to help increase health awareness among this target group. The MCAS program received the 2011 National Fathers Initiative Grant for capacity building.
- e. **Youth Athletic Program (YAP)** is an inclusive adapted sports program for at-risk youth, including those with disabilities and chronic illnesses. Launched in 2007, this program engages the children in physical activity and promotes healthy lifestyles. This program is funded in part by The HSC Health Care System Therapeutic Recreation Program in addition to The HSC Foundation.
- f. **Health Living Program (HLP)** provides obesity awareness/prevention and chronic disease management support to the entire community through free weekly exercise classes and other informational forums.
- g. **Family Navigator Program.** HSCSN partners with Advocates for Justice in Education (AJE) to train HSCSN member parents to become family navigators. Once training is successfully complete, the parent may work with HSCSN care managers and other family members to some degree to help with resource coordination and other family support services.

The National Youth Transitions Center (NYTC)

The HSC Foundation developed the NYTC in 2011 to help young people with disabilities achieve their highest level of independence. The center supports timely interventions for young people and their families to help them enter or re-enter the workforce and become productive members of the community. This innovative approach brings together resources from multiple organizations into a single location that provide transitions-related services, research, public policy, best practices, pilot projects, and evaluation. Training support includes government agencies, universities, and policy makers.



More than 45 partners participate in our collaborative efforts. A complete list of these organizations can be viewed on the center's website at www.thenytc.org. The center's partners bring their expertise and resources to create successful programs that serve as models for communities across the country. This community initiative helps to close gaps in available services needed by the disability community to improve overall health outcomes and experiences. Offered services include: (1) school-to-work readiness training, (2) family education and support, (3) personal development and leadership training, (4) career counseling and exploration and (5) work-based learning.

Two signature Foundation programs that are part of the Youth Transitions Initiative are (1) The Life Enrichment Awards Program (LEAP) and (2) the Advocates in Disability Award (ADA) program. Both are administered by The HSC Foundation and supported by the National Youth Transitions Center and other community partners. LEAP is an annual financial award that provides goods and services to youth and young adults with disabilities in transition to adulthood. The ADA program is also a financial award is given annually to a young individual with a disability between the ages of 14 and 26, who has dedicated their time to positively impacting the lives of individuals with disabilities and their families. It provides financial support for an innovative project that serves and empowers individuals with disabilities. Both programs enhance the disability community by adding quality-of-life experiences and additional social support.

HSC Home Care, LLC

The HSC Foundation funded the development of this home care agency in 2008 to respond to needs in the community for a specialized pediatric home care service. It serves a predominantly Medicaid population who before its existence had very few options for the level of expertise required for children facing long-term disabilities or chronic conditions.

The HSC Pediatric Center

The HSC Pediatric Center has served a population that has been approximately 90 percent Medicaid since it became a hospital in the mid-1950s. The reimbursement has rarely been at or above costs, and many medically needed services provided to this indigent population were never adequately covered by the payer mix. Disproportionate Share Funds allocated to cover Medicaid payment shortfalls were severely reduced in the District beginning in 1996. Since that time, the operating cost of caring for patients has significantly exceeded payment and has resulted in substantial Medicaid uncompensated care costs (UCC). The HSC Foundation has underwritten Medicaid UCC at HSC PC in excess of \$10 million since 2007. This financial support facilitated continued quality, medically needed and mission driven care delivery to an indigent population.

HSC PC also provides community benefit activities that include: community health education, community health research and coalition building, in-kind donations of equipment and space, and dedicated volunteer staffing. Both HSCSN and The HSC Foundation developed or supported additional community programs that would help the chronically disabled community avoid or lessen institutional care days and improve their overall quality of life.

Community Health Needs Assessment (CHNA) Goals

The HSC Pediatric Center CHNA purposefully evaluated indicators affecting the health needs and the health outcomes of pediatric populations with special health care needs and income challenges. Pursuant to these goals, this CHNA identified the following areas of unmet need based on input from members of the health care community, The HSC Health Care System leadership, and other key stakeholders:

- Lack of adequate insurance coverage for needed specialized inpatient and outpatient services,
- Lack of specific clinical services proven to improve health outcomes, and
- Social and economic barriers that hinder access to effective health and related social services.

The HSC Pediatric Center carefully evaluated these unmet needs to identify services or activities that could effectively address each need. We then devised several operational solutions that are within the Pediatric Center's capabilities. The identified solutions were designed to help both The HSC Pediatric Center and The HSC Health Care System begin to address the gaps in access to or delivery of quality services for our community.

CHNA Methodological Approach

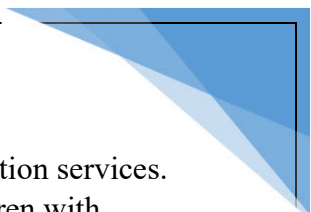
The HSC Health Care System engaged with community leaders and stakeholders, and public health experts familiar with the health needs of the high risk pediatric population. All were interviewed using structured interview tools or in open conversations designed to address the identified health care needs and issues within our patient community.

Next, we gleaned data from both the *2014 District of Columbia Community Health Needs Assessment* and the *2014 State of Maryland's Public Health Needs Assessment* to examine whether these states had identified additional health needs not captured during our interviews. We also examined comparable claims data from proprietary and public health organizations. Published articles produced by hospitals and health care systems, academic institutions and state partners, including other state government agencies, were reviewed to identify unmet needs for this population as well.

A complete bibliography and list of community participants can be found at the end of this report.

Summary Findings and Implementation Plan Overview

Our findings support a continuation of three of the same unmet needs addressed in HSC PC's 2012-2014 CHNA and published data related to children with special health care needs. As explained earlier, there continues to be a lack of insurance coverage for highly unstable inpatients with multiple disorders who cannot be safely discharged to home or a lower level of institutional care. Lack of insurance coverage also extends to state Medicaid programs who do not reimburse for needed specialized outpatient rehabilitation services outside of their state even though the services are not conveniently (within 50 miles) provided within their state. There is also a lack of needed integrated care that includes non-physician outpatient behavioral services and social services critical to medical success. Children with autism and developmental



delays (ages 0-3) are most impacted by the lack of the integrated outpatient, early intervention services. Lastly, there remains a need for better care coordination or wrap-around services for children with disabilities that incorporates health providers, care managers, and expanded community services to insure successful outcomes for an income challenged community.

Based on our findings, The HSC Pediatric Center has adopted the following 2015-2017 Implementation Plan initiatives:

- Continue charity services at HSC PC for non-covered, medically necessary outpatient rehabilitation services.
- Open an *Advanced Care Center (ACC)* at HSC PC focused on outpatient early intervention for children with autism and developmental delays, and
- Increase participation in local community partnerships to aid in the development of a more effective care-coordination model with specific focus on social services and related community resources.

The HSC Pediatric Center will also continue to collaborate with the District of Columbia and Maryland Medicaid agencies to address any additional needed services like, therapeutic day care or after-care school and summer programs. Components of this 2015-2017 Implementation Plan will be incorporated into ***The HSC Health Care System's Five-Year Strategic Plan Report***. Consistent with our mission, The HSC Health Care System may undertake other initiatives that are beyond HSC PC's scope to ensure that the identified unmet needs of our service population are met. However, there continues to be some community needs, such as a lack of adequate specialty physicians, that neither HSC PC nor The HSC Health Care System are equipped to address. We will however, continue to promote their development within the provider community and assist in program design and modeling to optimize health outcomes,

The remainder of this report provides a more detailed description of the CHNA methods, findings, and the 2015-2017 Implementation Plan.

II. Detailed Findings and Implementation Plan

Community (Patient) Demographics

Census information for 2010 and estimates for 2014 were reviewed to profile patient population trends within HSC Pediatric Center’s community. As presented in Table 2, the population growth for the District of Columbia and suburban Maryland and Virginia averages 21 percent. Estimates show that the pediatric population (including those age 20 and under) only grew by 2 percent between 2010 and 2014.

Table 2. Overall Population in Washington, DC Metropolitan Area

	Prince George’s, Montgomery, and Ann Arundel Counties, Maryland	District of Columbia	Fairfax, Arlington Counties, Virginia and Alexandria City
2010 – Total Population	2,372,853	601,723	1,428,319
2014 – Total Population (projections)	2,495,010	658,893	1,515,021
Percent Change	5%	10%	6%
Children Aged <21			
2010 Census	659,064	136,236	357,607
2014 Projections	642,007	137,265	366,917
Percent Change	-2.59%	0.76%	2.60%
<u>Source: US Census Data published by FactFinder.com</u>			

Public health experts estimate that 6 to 18 percent of the total child population have a chronic or medically complex condition that would qualify for services at HSC PC. Results from the U.S. Department of Health and Human Services (HHS) 2006 survey as published in the District’s 2010 Community Health Needs Assessment indicate that “... *in DC an estimated 10.2 percent of children birth to age 5, 18.6 percent of children ages 6 to 11, and 16.7 percent of children ages 12-17 are classified as having special health care needs.*” We used a conservative estimate of 6 percent to compare that to the SSI count, as the potential population that would benefit from HSC PC services.

Table 3. SSI and Chronic Needs Children in the Washington, DC Area

SSI ANALYSIS - DC AND SURROUNDING AREA				
Location	Total all	SSI Children ¹ Age <18	Total Population² Age <18	Chronic Needs ³ Age <18
District of Columbia	601,723	4,079	101,089	6,065
Prince George's County, MD	863,420	2,720	206,357	12,381
Montgomery County, MD	971,777	1,378	233,226	13,993
Anne Arundel County, MD	537,656	1,371	125,273	7,516
Arlington County, VA	207,627	125	32,597	1,956
Fairfax County, VA	1,081,726	835	262,859	15,771
Alexandria, VA	139,966	148	23,934	1,436
Totals	4,403,895	10,656	985,335	59,118
SOURCE: Social Security Administration, Master Beneficiary Record (OASDI Benefits),				
100 per cent data . Children are defined at 18 or under. Data as of December 2014				
² The 2010 US Census. Per the American Academy of Pediatrics, between 6% and 32% of children have chronic medical needs. We used the lowest or 6% in our calculation of children with chronic needs.				

As shown in Table 3. above, an estimated 59,118 children with special health care needs comprise the Pediatric Center’s service area in the under 18 age cohort. According to the District Department of Health, approximately 50 percent of youth live in either Ward 7 or Ward 8. These numbers would be slightly higher if “children” were defined as up to or through age 21.

Table 4. Special Needs Children by Type of Condition and County

Estimated Special Needs Population by Major Disease Categories					
	CSCHCN AGE (<19)	Cerebral Palsy, Dev. Delays and Failure to Thrive	11 Other Physical Health Categories	Asthma, Hemophilia, and Infectious Diseases	Behavioral Health Diagnoses
HSCSN Mbrs. - Qual. DX - 2015	4,098	295	1,142	237	2,401
% HSCSN Qualifying DX - 2015	100%	7%	28%	6%	59%
District of Columbia	6,065	425	1,698	364	3,578
PG County MD	12,381	867	3,467	743	7,305
Montgomery County MD	13,993	980	3,918	840	8,256
Anne Arundel County MD	7,516	526	2,104	451	4,434
Arlington County VA	1,956	137	548	117	1,154
Fairfax County VA	15,771	1,104	4,416	946	9,305
Alexandria VA	1,436	101	402	86	847
Totals	59,118	4,138	16,553	3,547	34,880

The table above presents broad disease categories that make up the estimated special needs population based on data captured by Health Services with Children with Special Needs, Inc., a dedicated health plan for Supplemental Security Income-eligible youth and young adults in the District of Columbia. Children are referred to HSCSN for enrollment based on SSI or pending qualification. HSCSN disease profiles extrapolated to the entire population that comprises the HSC PC service area provides a fair representation of the specific health care conditions within our catchment area.

Despite the wider range of chronic disease represented within HSC PC’s catchment area, the Pediatric Center only has the capacity to treat a subset of the qualifying conditions. A large percentage of children with special health care needs have a behavioral health diagnosis and are often treated at a psychiatric hospital or other related specialty institutions. Other high need diagnoses such as HIV or Sickle cell disease are treated at higher level acute hospitals with intensive care units and emergency rooms. Primary conditions treated at HSC PC require longer term transitional care or specialty rehabilitation care prior to their discharge to home or nursing/group home. Such conditions include cerebral palsy, anoxic brain damage, spina bifida, failure to thrive related to prematurity, chronic lung disease, and intestinal or other feeding disorders.

Behavioral health disorders represent the largest percentage of the special needs pediatric population (55%) in the District of Columbia, with similar findings in Maryland.

Community Input and Data Sources – Methodology

Our assessment began with a comprehensive published literary review, including public health assessments completed by state agencies and local hospitals and health systems for calendar year 2014. We cast a wide net to identify health care needs and recommended solutions for improved health outcomes for the pediatric special needs population. Reviewing published articles and completed assessments provided for a thorough

review and aided us in formulating interview tools that were relevant and consistent with industry best practices for assessing our population.

Next, we reviewed secondary data and published statistics provided by national and state governments to fully capture the medical conditions that are common within HSC PC's service population. HSCSN claims data were used to help focus our review of service providers and geographic areas with the most care needs. This data also refined our survey/interview questions to address significant gaps in services so we could better examine reasons for the gaps.

Lastly, we surveyed and held facilitated phone calls with public health experts and community stakeholders, to identify unmet service gaps. The following individuals were contacted:

- Medical directors from The HSC Pediatric Center and Health Services for Children with Special Needs, Inc. (HSCSN),
- Representatives and members of the local community, including medically underserved, low income and minority populations in the community served by HSC PC,
- HSCSN Care Manager team leaders, and
- Public health agencies in the District and the state of Maryland who support or facilitate service access for the disability community.

Survey participants also pointed us to 'key' providers in the community for particular services indicated for this population. Care managers at HSCSN and HSC PC identified 'key' providers as well, based on their particular expertise in dealing with special needs populations. We profiled their availability in terms of geographic proximity, Medicaid acceptance, and timely available appointments. In summary, we interviewed behavioral health providers, developmental providers, and physical medicine and rehabilitation physicians.

Information captured from the aforementioned sources were used to: (1) confirm unmet health and service needs, (2) formulate feasible implementation approaches, and (3) help develop HSC PC's implementation strategies for the next three years.

Key Findings

The HSC Pediatric Center Community has three primary unmet health needs, which the hospital has used to develop implementation plans that have considered strategies set in place by the District of Columbia and Maryland state governments. Those three primary unmet health needs include:

- Lack of adequate insurance coverage for needed specialized inpatient and outpatient services,
- Lack of specific clinical services proven to improve health outcomes, and
- Social and economic barriers that hinder access to effective health and related social services.

For each unmet need, the assessment details findings demonstrating these needs and HSC PC's recommended implementation plan to address each need as presented below.

Unmet Need 1: Underinsurance

According to 2014 District of Columbia Community Health Needs Assessment, “... *early expansion of Medicaid eligibility under the Affordable Care Act has led to insurance coverage for 96 percent of children living in the District – the second highest insurance rate in the nation after Massachusetts.*” However, some subgroups of children with special health care needs are underinsured; Medicaid benefits do not cover some health care expenditures such as certain durable medical equipment (DME), medical supplies, rehabilitation therapies outside of certain jurisdictions despite no comparable services within their covered jurisdictions, and non-covered “medically necessary” long term care days that are due to unsafe discharges. There is also a lack of coverage for certain outpatient mental health services and dental care.

HSC PC primarily serves populations that either qualify for Medicaid or some form of Medicaid Waiver coverage. For Maryland residents not covered by Medicaid, outpatient services are paid for by help from local children’s hospitals, school programs, and other community organizations. Virginia Medicaid continues to not cover outpatient services rendered outside of the state except for physician office levels of care. As a result, specialized outpatient rehabilitation services rendered at HSC PC continue to go uncovered. Similar service is offered 100 miles away from HSC PC in Richmond, Virginia.

Health care experts cited other examples of limited coverages during their interviews. There has been noted limited coverage for medically necessary non-covered days at the end of an inpatient stay. There have been several instances at HSC PC in which a child is scheduled to be discharged but the home environment is a medical risk or the caregiver is ill-prepared for required at-home patient care. As a result, discharge to home is often delayed for a day or more. However, Medicaid and Medicaid managed care plans often do not pay for these days.

As a result, The HSC Pediatric Center continues to offer rehabilitation services to Virginia Medicaid patients as a charity or community benefit. The HSC Pediatric Center also covers medically necessary non-covered days as part of our charity care program and continues to follow specific community benefit requirements below for non-profit hospitals:

- A written and published policy explaining eligibility for charity care or financial assistance as well as how patients can receive this assistance,
- Charges to impoverished patients receiving medically necessary services that are discounted or waived based on published federal poverty guidelines and reduced to an average charge accepted by commercial payers, and
- Hospital policy and operational practices to make reasonable efforts to determine eligibility for financial assistance before any collection activities are pursued.

The HSC Pediatric Center will implement the initiatives below to address unmet need due to lack of insurance coverage for additional services.

The HSC Pediatric Center 2015-2017 Implementation Plan (recommended solutions)

1. Dedicate additional resources to handle patient financial assistance to help patients in need to qualify for charity services at HSC PC.
2. Continue to treat Virginia Medicaid patients for outpatient rehabilitation services at HSC PC as a charity benefit.
3. Pursue collaboration with health care providers in Northern Virginia to offer outpatient services for patients with special health care needs.
4. Cover unpaid inpatient days that HSC PC deems as unsafe discharge until a safe transition can be made. We will continue our work with local agencies and payers to improve both insurance coverage and agreed-upon safe discharge results.

Unmet Need 2: Lack of Needed Clinical Services to Improve Health Outcomes

Improved health outcomes for HSC PC's pediatric population has a different meaning given the level of severity of the populations' health conditions. To improve health outcomes for our population means the following:

- Quality of life,
- Minimized pain, suffering or discomfort,
- Minimized emergency care, and
- An optimum level of functioning and independence relevant to the specific chronic condition to prevent additional co-morbidities or other health issues.

It has proven difficult to balance the myriad of services needed to achieve these goals. Additionally, it is challenging to achieve these goals with current available services within the Pediatric Center's catchment area. The current number of Medicaid providers in HSC PC's catchment area that provides needed services is inadequate and often inaccessible to HSC PC's population. Currently, there is a documented shortage of providers serving Medicaid pediatric populations in Anacostia and Columbia Heights, where 71 percent of low-income children reside.

Within the catchment area, there continues to be a deficit of providers in the following specialties: developmental pediatrics, behavioral health, and physical medicine and rehabilitation (PMR). HSC PC has experienced an increased demand for appropriate and effective services for adolescents and young adults with conditions like autism and related developmental and behavioral disorders.

As reported by the Centers for Disease Control and Prevention, statistics shows that the prevalence of autism in children ages 3 to 17, increased from 80 percent from 2011-2013 to 2014. Researchers now estimate that the prevalence is now 1 in 45 (or 2.24 percent). The prevalence of intellectual disabilities remains at 1.1 percent and the prevalence of other developmental disabilities was reported to be 3.57 percent in 2014. Studies have also shown that children diagnosed with autism often have higher rates of co-morbidities. 62.6 percent of children with autism also report having learning disabilities, while 42.8 percent also have attention-deficit/hyperactivity disorder or ADHD.

The need for services continues to far exceed the available resources leaving many with these conditions and their families in programmatic and financial limbo. HSC PC experts have expressed a need for more early intervention therapeutic and other services for children with developmental delays and their families. Currently, there are limited early intervention programs in HSC PC's catchment area. Coordinated services offered through early intervention programs are essential to treating children with disabilities in a timely fashion in order to make a difference.

The HSC Pediatric Center 2015-2017 Implementation Plan (recommended solution)

1. Open an ***Advanced Care Center (ACC)*** focused on early intervention for autistic and developmentally delayed children.

Unmet Need 3: Social and Economic Barriers that Hinder Access to Care

This assessment has highlighted barriers to quality care and outcomes for the Medicaid pediatric population. These barriers include a number of social determinants for this population including poverty, language barriers, homelessness and illiteracy. Most members of this community also has limited access to needed services. Health care delivery system is a fragmented system that often fails to consider the social issues members face that challenge health maintenance. Other members of the community have raised concerns that inadequate cultural competency restricts social and health service agencies in properly dealing with residents from diverse racial and ethnic backgrounds.


An article published in *Pediatrics* titled, 'What Will Open the Doors for Children and Youth with Special Health Care Needs from Traditionally Underserved Communities?' states that...

"The prevalence of these conditions of poverty undermines and complicates the ability and capacity of families to negotiate and coordinate so many service and care needs simultaneously, especially when resources are frequently organized in separate agencies that are not integrated. Agencies and resources are often limited by variable but ongoing financial constraints, often without the ability to develop an appropriate maintenance strategy plan."

The article also describes barriers in terms of "... high needs and demands, underreporting of problems, limited family capacity, inadequate professional knowledge for a population that depends on and interacts with the medical, education, and social systems in the community on a highly frequent basis." Workable solutions for these barriers still have not been identified after years of concerted wide spread community and governmental efforts. The overall consensus continues to be the idea of the medical home approach or targeted care coordination.

Caregivers have described challenges with understanding the complexities of their child's chronic condition and other health literacy and trust issues with treating physicians.

The HSC Pediatric Center has limited capacity to implement a medical home due to its delivery model. The exception is the ACC service that will be implemented in 2016 which will demonstrate a wrap-around model



for a limited service and population. Except for the ACC, it would be difficult for HSC PC to facilitate coordinated care beyond what hospital patients needed during admissions/registrations or discharge planning. These issues are better handled by sister organizations HSCSN and the HSC Foundation whose missions more easily encompass these initiatives and challenges. HSC Pediatric Center can and will play more of a community-wide role as it pertains to parent education, trainings, and empowerment. We will also provide a demonstration model with the ACC that will hopefully promote success in other outpatient clinic efforts for this population.

The HSC Pediatric Center 2015-2017 Implementation Plan (recommended solutions)

To address CHNA findings in this area, HSC PC will implement the following strategies designed to reduce barriers to needed care by its population:

- Share data on successes and lesson's learned with the implementation of the ACC which will incorporate a care-coordination or wrap-around care component.
- Participate in the initiatives implemented by the District of Health Care Finance including, DC State Innovation Model Committee Meeting, to voice the concerns of caregivers of children with special health care needs and to offer input in the design of new District-wide health initiatives focused on targeting social health determinants.
- Foster new partnerships with community organizations to create new programming to train parents and/or caregivers of children with special health care needs. HSC PC will also continue our caregiver support classes and forums for the community at large.

Summary and HSCPC Implementation Plan

The HSC Pediatric Center in collaboration with The HSC Health Care System completed this comprehensive health needs assessment to strategically guide future operations for the betterment of the community we serve. Based on the findings presented, HSC PC has adopted implementation strategies designed to improve health care access, health outcomes, and meet other identified health care needs for populations with high medical risk due to social health determinants and income challenges. These implementation plans are outlined in Table 6 along with the assessed needs to which they correlate.

The mission of The HSC Health Care System is to ensure the highest possible quality care provision and health outcomes for the chronically disabled community. While HSC PC will implement the specific plans below based on the needs assessment, The HSC Health Care System will continue to provide community benefit activities described herein and embrace new activities to address services needed by disabled populations per our mission.

Table 6. – HSC Pediatric Center Implementation Plan

Assessed Need	2015-2017 Implementation Plan
Lack of insurance coverage for available services	<ol style="list-style-type: none"> 1. Continue to provide charity services for patients (a) needing non-covered Medicaid services that are medically needy and (b) meeting the charity definition based on Federal poverty guidelines. 2. Continue to follow the specific community benefit requirements for non-profit hospitals which include financial counseling, uniform charging, and published charity care policies and annual amounts.
Demand for new clinical services to improve health outcomes	<ol style="list-style-type: none"> 1. Open an <i>Advanced Care Center (ACC)</i> to provide outpatient early intervention for children with autism and developmental delays.
Social and economic barriers that hinder access to services	<ol style="list-style-type: none"> 1. Collaborate with community partners, as required, to define an effective medical home model that may be tested for improved health quality and cost effectiveness.

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Bibliography

- Cha, Ariana. (2015, November 13). Retrieved from Washington Post:
www.washingtonpost.com/news/to-your-health/wp/2015/11/13/autism-cases-in-u-s-rise-to-1-in-45-a-look-at-who-gets-the-diagnosis-in-8-simple-charts/
- Chandra, A., Janice, B. C., & Ruder, T. (2013). *District of Columbia Community Health Needs Assessment*. Arlington: RAND Corporation.
- Garcia, J., Johnson-Clarke, F., & Chichester, C. (2014). *District of Columbia Community Health Needs Assessment, Volume 1*. Washington, DC: District of Columbia Department of Health.
- Gerhardt, P. F. (2009). *The Current State of Services for Adults with Autism*. New York: Organization for Autism Research.
- Inkelas, M., & Raghavan, R. (2007). Unmet mental health need and access to services for children with special health care needs and their families. *Ambulatory Pediatrics*, 431-438.
- Internal Revenue Service. (2015). *Hospital Compliance Project Interim Report*.
- Kennedy Krieger Institute. (2013). *Community Health Needs Assessment Changing Maryland Communities for the Better*. Baltimore: Kennedy Krieger Institute.
- Maryland Department of Health and Mental Hygiene. (2012). *Maryland State Disabilities Plan 2012-2015*. Baltimore: Maryland Department of Disabilities.
- MedStar Health. (2015). *Community Health Needs Assessment 2015*. MedStar Health.
- Nageswaran, S. (2009). Respite Care for Children with Special Health Care Needs. *Arch. Pediatric Adolescent Medicine*, 49-54.
- Oswald, D. (2011). Disparities in the Clinical Encounter: Virginia's African American Children with Special Health Care Needs. *Pediatrics*, 1-8.
- Tang, M., Hill, K., & Boudreau, A. (2008). Medicaid Managed Care and the Unmet Need for Mental Health Care among Children with Special Health Care Needs. *Health Services Research*, 882-900.
- United States Census Bureau. (2014). Retrieved from
<http://factfinder.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t>
- University of Maryland Medical Center. (2015). *Community Health Needs Assessment & Implementation Plan*. Baltimore: UMMC.
- Virginia Hospital Center. (2014). *A Community Health Needs Assessment*. Arlington: Virginia Hospital Center.