The Children’s Institute of Pittsburgh
Community Health Needs Assessment 2015

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EXECUTIVE SUMMARY

The Children’s Institute of Pittsburgh is a leading center for pediatric rehabilitation, complex medical care, education for children with special needs and family placement, preservation, reunification and enrichment services. Established in 1902, The Children’s Institute is an independent, nonprofit, licensed organization in Pittsburgh dedicated to improving the quality of life for children, young people and their families by providing a specialized continuum of services that enables them to meet their potential. It is the only organization in Pennsylvania offering a hospital, a school and a social services agency. This unique, comprehensive approach sets the organization apart.

The U.S. Congress passed the Patient Protection and Affordable Care Act in March, 2010. The legislation covers many changes to the nation’s health care system, including the requirement that nonprofit hospitals must conduct a Community Health Needs Assessment (CHNA) every three years. Through the CHNA a hospital must define the community it serves, assess the health needs of that community, and describe how the hospital plans to address the identified needs.

The 2012 CHNA conducted by The Children’s Institute which coincided with the fiscal year ending June 30, 2012 was extensive, and included input from a variety of stakeholders including case managers, community advocates, public officials, funders and school districts. The resulting assessment identified four significant health needs rated with a high priority:

- **Care Coordination**: Support and coordination of medical and social services for children and youth with multiple ongoing medically complex conditions
- **Behavioral Health**: Specialized behavioral health services for patients, students, child welfare service clients and other children with special health care needs
- **Transition Services**: Comprehensive day programs and services to assist young adults with special needs transition from school to adulthood at age 21
- **Telepresence**: Increased virtual access to medical and other services through technology for children and youth with special health care needs and their families especially those living in remote, rural and underserved areas

These needs were used to shape The Children’s Institute’s strategic initiatives that continue to be implemented throughout the organization’s three components. Due to the magnitude of these needs the same four initiatives remained our focus during the 2015 needs assessment process. During the three years following the 2012 CHNA, we continued to solicit input from persons who represent the broad interests of the community that we serve, namely the children and youth with special health care needs and their families living in Allegheny County and Western Pennsylvania, and found these four issues are still prevalent needs in the community. We utilized the input we gathered to further refine and implement plans to address these four significant health needs.

This report contains background information on The Children’s Institute, a definition of the community we serve, a description of the process and methods we used to conduct the 2015 CHNA and to solicit community input, how we prioritized the identified needs, the resources currently available to the community, and an evaluation of the impact of actions we have taken toward implementing the initiatives.
BACKGROUND

The Children’s Institute of Pittsburgh is dedicated to improving the quality of life for children, young people and their families by providing a specialized continuum of services that enables them to reach their potential.

Founded in 1902 as the Memorial Home for Cripple(d) Children, The Children’s Institute is an independent, licensed, nonprofit organization providing pediatric rehabilitation, complex medical care, special needs education and family placement, preservation, reunification and enrichment services. It is the only organization in Pennsylvania offering a hospital, a school and a social services agency.

HIGHLIGHTS

- Only free standing pediatric rehabilitation specialty hospital in Pennsylvania
- Ten Autism Classrooms with specific curriculum and environmental design
- Three community locations offering outpatient therapy services
- Host of 2015 national clinical conference on Prader-Willi syndrome
- Over 2,000 children and families served each year through fostering, adoption, and

The Hospital

- One of only 28 facilities in the country accredited for Inpatient Pediatric Rehabilitation by the Commission on the Accreditation of Rehabilitation Facilities (CARF), and the only free-standing pediatric rehabilitation specialty hospital in Pennsylvania.
- Also accredited by CARF for Inpatient Pediatric Brain Rehabilitation (one of only seven in the country) and Single Discipline Outpatient Pediatric Rehabilitation (one of only 10 in the country).
- The Center for Prader-Willi Syndrome offers the world’s only comprehensive, hospital-based inpatient program for medical, behavioral and rehabilitation management of both children and adults with this rare genetic disorder.
- In Fiscal Year 2014, 6,886 children and their families were served through 317 inpatient discharges and 71,843 outpatient physician and therapy visits.

The Day School

- An approved private school for children ages five through 21 challenged by complex and severe disabilities such as autism, cerebral palsy and other neurological impairments.
- Nearly 200 students are enrolled in the school, coming from 67 school districts.
- Ten classrooms with autism-specific curriculum within self-contained Autism Pod with incandescent lighting, acoustic ceiling tiles to dampen sound, a separate dining area and a sensory room.
- Five Adult Prep classrooms for students age 18 to 21 that focus on matching student’s abilities with appropriate options for work and community involvement.

Project STAR

- Social Services organization promoting the right of all children to grow in a safe, nurturing, lasting family.
- Provided 2,021 children and families with services in Fiscal Year 2013 including family recruitment, child placement, family preservation, reunification, foster care, adoption and enrichment programming.
From Fiscal Year 2012 through 2014 an average of 30% of all inpatients resided in Allegheny County, 65% resided in Western Pennsylvania (including Allegheny County), and 71% in Pennsylvania. A significant portion (28%) came from outside of Pennsylvania to be treated at The Children’s Institute. The rate of outpatient residents of Allegheny County is even higher, with a three-year average of 60%.

There are over 235,000 children under age 18 in Allegheny County, representing nearly 20% of the total population, and a quarter of all households have dependent children.

The median household income is $51,366. Sixty-five percent of the population are home owners, and the median value of owner-occupied housing units is $122,400. Nearly 13% of the population lives below the poverty level.

The Children’s Institute serves patients and families from many communities across Pennsylvania, the country and the world. When the 2012 CHNA was conducted, we considered the community served using the American Hospital Association’s definition of the geography from which 70% of the hospital discharges originate. Since the final IRS guidelines released in December 2014 do not include such a specific definition, and since the majority of children and youth who will benefit from our solutions to the significant health needs identified in our last CHNA reside in the immediate Pittsburgh area, we redefined the community served to be Allegheny County alone.

<table>
<thead>
<tr>
<th>Metric</th>
<th>Allegheny County</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>1,234,342</td>
</tr>
<tr>
<td>Pediatric Population (age 0-17)</td>
<td>235,400</td>
</tr>
<tr>
<td>Non-White Population</td>
<td>20%</td>
</tr>
<tr>
<td>Total Households</td>
<td>526,004</td>
</tr>
<tr>
<td>Households with Children</td>
<td>25%</td>
</tr>
<tr>
<td>Median Household Income</td>
<td>$51,366</td>
</tr>
<tr>
<td>High School graduate or higher (age 25+)</td>
<td>92.9%</td>
</tr>
<tr>
<td>Bachelor’s Degree or higher (age 25+)</td>
<td>35.9%</td>
</tr>
<tr>
<td>Home Ownership Rate</td>
<td>65.5%</td>
</tr>
<tr>
<td>Median value of owner-occupied housing</td>
<td>$122,400</td>
</tr>
<tr>
<td>Persons below poverty level</td>
<td>12.9%</td>
</tr>
</tbody>
</table>

Sources:
US Census Bureau, State and County QuickFacts 2013 data
Truven Health Analytics/The Nielsen Company 2014/2015 data
While children under 18 make up 19% of the population in Allegheny County, Seniors age 65+ make up nearly the same portion at 18%. Allegheny County is predominantly Caucasian, with Whites comprising 80% of the population. The 20% minority population is represented mainly by African Americans at 13%.

High School is the highest education level attained by the largest portion of the population represented by 269,596 residents or 30%. A significant number have attained a Bachelor’s Degree (21%) or a Graduate Degree (15%) primarily due to Pittsburgh being the seat of many distinguished institutes of higher learning including the University of Pittsburgh, Carnegie Mellon University, and Duquesne University.

Fifty-seven percent of the pediatric population in Allegheny County is covered by private insurance, 89,060 (38%) are covered by Medicaid and 11,440 (5%) by CHIP. These children who are covered by government funded or subsidized insurance represent a large portion of our patients.
The special needs pediatric population that The Children’s Institute serves includes a variety of functional limitations, disabilities and congenital conditions including autism, neurological impairment, and intellectual and developmental disabilities.

There are over 21,000 students enrolled in special education in Allegheny County, 8,500 of them (0.4%) with multiple disabilities. 3,288 children (1.4%) have an intellectual disability and 7,986 (3.4%) have difficulty with self-care activities such as eating, bathing and toileting.

Over 2,800 special education students in Allegheny County are categorized as “Other Health Impairment” which is defined as having limited strength or alertness due to chronic or acute health problems that limit their ability to learn.

Over 4,200 children of all ages and over 3,400 within the special education system are diagnosed with autism.

Another 2,000 special education students in Allegheny County suffer from emotional disturbances.

As this population ages out of the special education system at age 21, their families are faced with limited choices due to their significant needs such as inability to manage activities of daily living and needing constant supervision.

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### Table 2. Functional Limitations in Pediatric Population

<table>
<thead>
<tr>
<th>Metric</th>
<th>Allegheny County</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism, Asperger’s, PDD or ASD</td>
<td>1.8%</td>
</tr>
<tr>
<td>Developmental delay that affects ability to learn</td>
<td>3.0%</td>
</tr>
<tr>
<td>Intellectual disability or mental retardation</td>
<td>1.4%</td>
</tr>
<tr>
<td>Difficulty with self-care activities</td>
<td>3.4%</td>
</tr>
<tr>
<td>Difficulty with coordination or movement</td>
<td>3.2%</td>
</tr>
<tr>
<td>Speaking, communicating or being understood</td>
<td>5.8%</td>
</tr>
<tr>
<td>% of all students enrolled in Special Education</td>
<td>14.4%</td>
</tr>
<tr>
<td>Special Education enrollment</td>
<td>21,469</td>
</tr>
<tr>
<td>Autism</td>
<td>16.1%</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td>9.7%</td>
</tr>
<tr>
<td>Intellectual disability/mental retardation</td>
<td>6.7%</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>0.4%</td>
</tr>
<tr>
<td>Other health impairment</td>
<td>13.1%</td>
</tr>
<tr>
<td>Speech or language impairment</td>
<td>17.6%</td>
</tr>
</tbody>
</table>

Sources:

### Functional Limitations of Young Adult Population

- Could be taken advantage of by others: 92.7%
- Cannot manage activities of daily living: 83.3%
- Can never be left alone, or only for a short time: 80.0%
- Cannot demonstrate an understanding of space and time: 62.7%
- Requires 1:1 support for health and safety: 60.0%
- Has self-injurious behaviors: 32.7%
- Has medical/physical needs that require assit of medically trained professional: 27.3%

Source: Adults with Complex Transitions study, United Way of Allegheny County 21 and Able Project
PROCESS AND METHODS

In order to understand the needs of the community we serve and how to best meet those needs, the Board, leadership and staff of The Children’s Institute engaged in a rigorous strategic planning process that included internal and external stakeholder interviews, focus groups, surveys and market analysis. This process that began in 2011 culminated in the 2012 Community Health Needs Assessment (CHNA) which identified four significant health, social, behavioral and environmental needs of the underserved population of children and youth with special needs in our community. While conducting our current needs assessment, we found that these four needs continue to be prevalent. We therefore maintained a focus on these same needs, and will work toward enhancements to the programs and services that have been established.

The four significant health needs are:

- **Care Coordination** for children with complex medical conditions
- **Behavioral Health** services for children with developmental disabilities
- **Transition Services** for young adults aging out of special education
- **Telepresence** delivery of health, education, and other services

Once the leadership team determined that the needs identified in 2012 were still prevalent within our community, multidisciplinary workgroups were formed to continue to explore and enhance programming for each need. These workgroups consisted of staff responsible for business development, clinical, educational, and technical duties. The multidisciplinary composition of the groups ensured that all facets of the project were examined. In this way any potential obstacles were minimized or eliminated.
Each initiative was outlined and documented in the Strategic Initiative Dashboard along with other organizational initiatives. The workgroups utilized quantitative data such as internal reports and government and industry resources to analyze the market. This analysis was necessary to determine the estimated number and characteristics of children and youth who could be supported through each initiative. It also provided insight into other potential resources available (or lacking) to meet the significant health needs.

The groups also took into account qualitative data received through The Children’s Institute’s Family Advisory Council, results from a survey of parents of special needs children attending The Day School, and the plethora of input the leadership team received through their communications with government health officials and other parties with expertise in children with special healthcare needs. This qualitative data was indispensable in shaping the initiatives.

The analysis and plans developed by the workgroups were reported to organizational leadership monthly for review and feedback. The groups incorporated this feedback into planning discussions.

Each of the groups also considered the necessary financial and staffing resources, licensing and other regulatory requirements, and urgency of the target population’s need to determine the estimated feasibility and effectiveness of possible interventions. The Audit Committee and the Planning Committee each met twice a year and carried greater responsibility for reviewing the Strategic Initiative Dashboard and determining next steps for the projects.

Each quarter the workgroups updated the Strategic Initiatives Dashboard document to indicate all activities and planned tasks. This document was made available to the Board quarterly, and was officially presented and reviewed to them each May.
While the workgroups continued to translate the initiatives into action, The Children’s Institute’s leaders took every opportunity to engage with persons representing the broad interests of the community to solicit input in prioritizing the needs and in identifying potential resources to support our efforts to address the needs.

We solicited and incorporated feedback from families, legislators, physicians, public officials and other community stakeholders as well as subject matter experts at leading facilities within and outside the immediate community. Our leaders communicated with each source required by IRS Section 501(r) as well as additional sources:

**Government Health Departments**

**Methods:**
- One on One meetings at government offices in Harrisburg, PA
- Telephone conversations
- Budget Director, PA Department of Human Services (April 2015)
- Chair, PA House Health Committee (April 2013)
- Chair, PA House Majority Appropriations Committee (April 2013)
- Chief Medical Officer of Medicaid, PA Department of Human Services (April 2015)
- Chief of Staff (Senator Vance’s office) and Executive Director of the Public Health and Welfare Committee (April 2013 and April 2015)
- Chief of Staff, PA Department of Health (August 2013)
- Deputy General Counsel and Executive Director, PA House Health Committee (April 2015)
- Deputy Secretary, Office of Medical Assistance Programs, PA Department of Human Services (April 2015)
- Executive Deputy Secretary, PA Department of Human Services (April 2015)
- Executive Director, House GOP Appropriations Committee (April 2015)
- Secretary, PA Department of Health (August 2014)

**Medically Underserved, Low-Income and Minority Populations**

**Methods:**
- One on One meetings
- Telephone conversations
- Biannual meetings with regional school district’s special education directors
- Conferences focused on special needs population
- Research from advocates for special needs population
- Associate Chief Medical Officer, Children’s Hospital of Pittsburgh of UPMC (August and September 2014)
- Chief Executive Officer, Pediatric Specialty Care (August 2014)
- Chief Executive Officer, and Director of Patient Care Services, Shriners Hospitals for Children (August and October 2013, March 2014)
- Chief Executive Officer, The Bradley Center (August 2014)
- Chief Medical Officer, Children’s Hospital of Pittsburgh of UPMC (August 2014)
- Chief Medical Officer, The Bradley Center (August 2014)
- Director, Programs for Seniors and Persons with Disabilities at United Way of Allegheny County (Ongoing)
- Executive Director, The Early Learning Institute (January, February and September 2014)
- President and CEO, Allegheny Children’s Initiative/Partners for Quality, Inc. (August 2014)
- President and CEO, Pressley Ridge (February 2014)
- President, Children’s Hospital of Pittsburgh of UPMC (on quarterly basis)
- Special Education Directors of Armstrong, Fox Chapel, Franklin Regional, Peters Township, and North Allegheny school districts (ongoing)
- United Way of Allegheny County’s 21 and Able project’s Adults with Complex Transitions research study
Written Comments

- No written comments on the 2012 CHNA or Implementation Strategy were received

Other Sources

Methods:
- Tours of facilities delivering care to children with special needs
- Telephone conversations
- Experts invited to tour our facility
- Conferences and seminars

- American Hospital Association Regional Policy Board
- Chief Executive Officer, Franciscan Hospital for Children
- Chief Executive Officer, Southwood Psychiatric Hospital
- Chief Operating Officer, Franciscan Hospital for Children
- Children’s Hospital Association
- Hospital Administrator, Cleveland Clinic Children’s Hospital for Rehabilitation

The Children’s Institute’s leaders including the President and Chief Executive Officer, the Chief Operating Officer, the Chief Medical Officer, the Chief School Administrator, and the Chief Nursing Officer solicited input from experts and community representatives through one-on-one meetings, telephone conversations, tours of our facility and conferences and seminars concentrating on meeting the needs of the special needs population. Leaders also visited and toured other facilities that deliver care to children and youth with special health care needs to gain knowledge from best-in-class providers.

Highmark Blue Cross and Blue Shield and the Highmark Foundation were key partners in the development of the Care Coordination program. Highmark Blue Cross Blue Shield is a regional health insurer covering 3.2 million members in Western Pennsylvania and is the fourth largest Blue Cross and Blue Shield-affiliated company. The Highmark Foundation is a charitable organization, a private foundation and an affiliate of Highmark Inc. that supports initiatives and programs aimed at improving community health.

Beginning in 2012 and continuing through 2014 when the program was launched, leaders from The Children’s Institute consulted with Highmark’s Chief Medical Officer who is board-certified in pediatrics and in pediatric cardiology, and also with Highmark’s VP of Health Management Services. Highmark’s experience with Patient Centered Medical Homes and their Caring Program (a care coordination program for children with special health care needs) was valuable in building the best program for our population. Additionally, we applied for and received grant-funding from The Highmark Foundation to support our development of the Care Coordination program.

In addition to all regular workgroup, organizational leadership, Board and subcommittee meetings throughout the year, the general public was invited to attend a meeting of the Board each June.

Through a collaborative effort between leadership and business unit workgroups, we embarked upon the execution of projects that once fully implemented will greatly improve the health, social, behavioral and environmental conditions of the population we serve.
PRIORITIZATION OF NEEDS

The findings and recommendations of the workgroups were presented to The Children’s Institute’s Board. Each initiative was examined and assigned a priority based on the urgency of the need, the estimated feasibility of possible interventions, and the importance that our community placed on fulfilling the need.

While the community’s perception of need was easily recognized by the amount of feedback we received through our various efforts, the levels assigned to urgency and feasibility are defined below:

<table>
<thead>
<tr>
<th>Urgency</th>
<th>Feasibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>High:</td>
<td>High: Existing or easily attainable resources and limited regulatory/licensing obstacles</td>
</tr>
<tr>
<td>Moderate:</td>
<td>Moderate: Potential to attain resources and moderate regulatory/licensing obstacles</td>
</tr>
<tr>
<td>Low:</td>
<td>Low: No resources and extreme regulatory/licensing obstacles</td>
</tr>
</tbody>
</table>

After assigning the appropriate level to each significant health need, they were ranked as follows:

<table>
<thead>
<tr>
<th>Priority</th>
<th>Initiative</th>
<th>Urgency</th>
<th>Feasibility</th>
<th>Importance to Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Care Coordination</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>2.</td>
<td>Behavioral Health</td>
<td>Moderate</td>
<td>Moderate</td>
<td>High</td>
</tr>
<tr>
<td>3.</td>
<td>Transition Services</td>
<td>Moderate</td>
<td>Moderate</td>
<td>High</td>
</tr>
<tr>
<td>4.</td>
<td>Telepresence</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
</tbody>
</table>
Care Coordination
Care Coordination was determined to be the highest priority initiative due to the severity of the need of children with complex medical conditions. The Children’s Hospital Association estimates that between 1% and 4% of the pediatric population have complex medical conditions translating to between 7,700 and 31,000 children in Western Pennsylvania, and between 2,354 and 9,416 in Allegheny County alone. These medically complex children can have as many as 10 or 20 different health providers and allied health professionals involved in their care.

In addition to the severity of need among this population, we were supported in our effort by Highmark for clinical expertise and The Highmark Foundation for funding. This made the feasibility of implementing a program and the effectiveness of potential outcomes very high. It was also determined to be of high importance to parents in our community who lack proactive, centralized, seamless care coordination by professionals for their children with complex medical conditions.

Behavioral Health
Behavioral Health services for children and youth with developmental disabilities was perceived by the community as being highly important due to the lack of specialized psychiatric care in the community for this population. While we estimated the urgency to be moderate since there are some resources available we also estimated the feasibility to be moderate since our existing outpatient service component could be expanded and the possibility of a build-out of underutilized hospital space could offer inpatient services though it would take considerable planning and time to implement.

The analysis of our workgroups confirmed the need for specialized inpatient care for children with developmental disabilities through the PA Department of Health which reported only 144 of 614 psychiatric beds in Allegheny County licensed for pediatric patients. Additionally, the available resources do not provide the ideal environment for developmentally disabled children.

Transition Services
It was determined that though Transition Services are available in the community for young adults with special needs aging out of the school system, there is still a need for more resources. In order to determine what parents and other community leaders knowledgeable about the special needs population thought of options currently available and the urgency of the need for such services, we conducted a survey in November 2014.

The results overwhelmingly indicated a strong perceived need among the community for these services, and a particular interest in specialized services offered by The Children’s Institute. The results of our survey aligned with findings from the United Way of Allegheny County’s 21 and Able program’s Adults with Complex Transitions (ACT) survey launched in September 2012.
The study identified six areas requiring change and growth in the Western PA transition services market, one of these being “Building the capacity of day options to support individuals with the most complex needs.”

**Telepresence**
Although the utilization of telepresence in healthcare delivery is expected to increase in the future, because of the lack of immediate need and various challenges associated with delivering care in this way, this initiate was given a lower priority.

Our leadership committed to exploring the use of technology to increase accessibility and ensure that the needs of our community were met in new and innovative ways. A technological solution, in the form of telepresence, was also expected to reduce costs and improve the quality of delivered services.

Unfortunately, Pennsylvania does not have a telemedicine parity law that would require healthcare insurers to reimburse “virtual” medical visits in the same way in-person visits are reimbursed. Legislation has been introduced, but not passed. Until a parity law is enacted, it will not be feasible to implement this intended use of the telepresence platform.
RESOURCES POTENTIALLY AVAILABLE TO ADDRESS NEEDS

There are adequate services available in Allegheny and surrounding counties for the general pediatric population, however the special needs population served by The Children’s Institute does not have the same wealth of options available. While there are a number of providers and organizations offering outpatient medical therapy and social services in the area, few of them are able to provide the comprehensive, multidisciplinary, family-centered care delivered by The Children’s Institute. The Children’s Institute is the only free-standing inpatient pediatric rehabilitation facility in Pennsylvania and one of only 28 facilities in the country accredited for Inpatient Pediatric Rehabilitation by the Commission on the Accreditation of Rehabilitation Facilities (CARF), however there are a few facilities in the area that will take young adults (not children) for inpatient rehabilitation services.

Pediatric Inpatient Rehabilitation Services
- Children’s Hospital of Pittsburgh of UPMC
- Children’s Home
- Health South Harmarville
- Health South Sewickley
- UPMC Rehabilitation Institute at UPMC Mercy

Pediatric Outpatient Therapy Services
- Advanced Orthopaedic and Rehabilitation
- Allegheny Adult & Pediatric Therapy
- AOT, Inc.
- Apple Rehabilitation Services
- Aspire Pediatric Therapy
- Bradley Physical Therapy
- Center 4 Speech
- Centers for Rehab Services
- Children’s Hospital of Pittsburgh of UPMC
- Children’s Rehab Services
- Children’s Therapy Center
- Claire Vatz Speech Therapy
- Crossroads Speech & Hearing
- Drayer Physical Therapy
- East Suburban Sports Medicine
- Embrace the Child
- Excela Health
- Greater Pittsburgh Physical Therapy & Sports Medicine
- Hope Learning Center
- HVHS Signature Sports Care Program
- Laughlin Children’s Center
- New Steps Rehabilitation, Inc.
- Pediatric Therapy Specialists
- Physical Rehabilitation Services
- Positive Steps Therapy
- Rehabilitation Specialists, Inc.
- River Speech & Education Services
- Sensory Link Pediatric Therapy
- The Early Learning Center
- The Watson Institute
- Thrive Place

Special Education
- ACLD Tillotson School
- Easter Seal Society of Western PA
- New Story Monroeville
- Pace School and Pace Learning Center
- Pressley Ridge Day School and School for Autism
- Watson Institute
- Wesley Spectrum

Adoption/Foster Social Services
- Adoption Connections
- Auberle
- Center for Family Excellence
- Family Pathways
- Family Resources
- Holy Family Institute
- Pathways UPMC
- Pressley Ridge
- Three Rivers Adoption
- Three Rivers Youth
- Total Family Services
- Wesley Spectrum
- Youth Advocates Program, Inc.
Since The Children’s Institute conducted the 2012 CHNA, significant actions were taken on the highest priority need, Care Coordination. Progress was also made in meeting the Behavioral Health and Transition Service needs that were identified, but the regulatory environment has barred further movement toward the Telepresence need as it relates to telemedicine. The following pages describe the actions taken toward each significant health need, and the impacts that have been seen to date.

**Care Coordination**

The Care Coordination goal described in The Children’s Institute’s 2012 CHNA was to establish a medical home for children with special health care needs including a network of primary care physicians, registered nurses and social workers to provide primary health and care coordination services along the full continuum of care.

After multiple discussions and strategy meetings with collaboration partner Highmark, it was determined in August 2013 that hiring the necessary physicians as employees would not be cost-effective and would duplicate services already available in the community. Instead of developing a medical home model, it was determined that a care coordination model, staffed by care coordinators, health coaches and social workers, would be a better path to address the needs of the population. This approach also supports the Affordable Care Act’s desire for health care providers to explore how better health care can be delivered at a lower cost. The Children’s Institute’s Care Coordination “Proof of Concept” and ensuing payment model is a key element in how we are adapting to the changing health care environment.

In 2014 we hired key staff including care coordinators, health coaches, social workers and developed the Care Coordination structure with a triple aim: achieve improved health outcomes; improve quality of life; and reduce overall healthcare costs. The program was made available to children meeting the criteria of having complex medical conditions living within the 23 counties of Western Pennsylvania in July, 2014. As of May 2015 there were nearly 200 children and youth actively participating in the Care Coordination program.

In the fall of 2014 the Care Coordination team began extensive outreach efforts, raising awareness and gathering feedback from the community and various stakeholders including health insurers, health care providers and social service organizations representing the pediatric special needs population. Additionally, information about the program was sent to local physicians encouraging them to refer patients who could benefit from the program.

With guidance from our Research Director, the Director of Care Coordination designed a research project to determine whether the program achieves its objectives. Our Institutional Review Board approved the project in March 2015 and Care Coordination staff began following patients through the program, collecting their health status data and comparing it to a control group.
All participants receive a comprehensive medical and psychosocial assessment and a Care Coordinator develops a family-centered plan of care that includes partnering with the child's PCP and other medical providers and the facilitation of communication between the providers and the child's family. Ongoing reviews of each family's medical, social, educational, legal and general needs are conducted and families are connected with a wide range of community based social resources.

The pilot program has met the needs of children with complex medical conditions and their families just as we had hoped it would. Many financial stressors (utilities, cost of DME, Medicaid, SSI) and psychosocial needs (food, housing, transportation) have been identified and addressed for participants and their families. Beneficial outcomes have been realized including:

- Increased access to needed resources
- Increased patient compliance
- Increased physical/behavioral/cognitive functionality
- Decreased duplication of unnecessary services
- Decreased hospitalizations

We expect the Care Coordination demonstration project will result not only in improved care, but in cost savings, prompting payers to enroll children into the program with a per-member-per-month fee. The team continues to build a referral base through physician and hospital partnerships, to seek additional grant funding and program promotion opportunities, and to work with health insurers to negotiate contracts.

**Behavioral Health**

After identifying the need for greater access to outpatient behavioral health services, we reviewed existing staff and operational delivery structures making several operational changes including the establishment of the Pittsburgh Psychology Internship Consortium that gives us support from advanced doctoral students. These changes afforded increased capacity and gave us the ability to provide greater access to the community.

Outpatient behavioral health services have and continue to be offered to individuals from Project STAR, our social services agency, as well as to Pain Rehabilitation, Brain Injury, Concussion and Feeding & Swallowing patients. The services are also offered to any discharged inpatient, and through a pilot program, individuals with Prader-Willi syndrome and their siblings.

Through the third quarter of Fiscal Year 2015 we provided 83% more outpatient services than we did in the same period of Fiscal Year 2014, and 16% over the targeted initiative goal.

Our Chief Medical Officer and our behavioral health planning team visited best-in-class pediatric facilities to learn about their models for providing behavioral health services to children and youth with developmental disabilities. Meetings with the Pennsylvania Departments of Health and Public Welfare confirmed the need for expanded behavioral health services in our community.
Discussions about collaboration and support for a program offered at The Children’s Institute are ongoing with other psychiatric providers in the area.

We continue to explore the operational, staffing, architectural and financial logistics of opening an inpatient pediatric psychiatric unit within the current hospital that focuses on the treatment of children and adolescents with developmental disabilities, as well as pediatric Prader-Willi syndrome patients who have significant behavioral issues.

**Transition Services**

Beginning in July of 2012 and spanning two years, the curriculum for every grade of The Day School at The Children’s Institute was evaluated and revamped with the intended goal of preparing every student to eventually be ready to transition into adulthood at age 21.

We also implemented our Adult Prep program in 2012 as a pilot for students age 18 to 21. The program focuses on each student’s interests and needs, carefully matching their abilities with appropriate options for work and community involvement when they exit the school system at age 21. The pilot program that began with one classroom and has expanded into five.

Planning began in 2014 and continues to determine the curriculum, staffing and architectural needs of an Adult Training Facility (ATF) operated by The Day School. The services of an expert consultant from an existing ATF were engaged to help design the program, and ensure that all necessary elements are considered.

**Telepresence**

A range of opportunities to engage with other providers on behalf of our students and patients was identified, including virtual medical, education and family service programming that could complement in-person service delivery.

Telepresence equipment was purchased and installed in 2013. In April 2014, work teams were established and the teams met regularly to identify project initiatives, develop timelines for implementation, developing documentation for telepresence projects.

Through the investigation and implementation process, we encountered many obstacles, chief of them the lack of a telemedicine parity law in Pennsylvania. Instead of abandoning the telepresence concept entirely, and with the hope that legislation will be enacted in the future, we explored and are currently implementing the utilization of the telepresence equipment in non-healthcare delivery methods that are improving the social and environmental situations of our special needs population.

The equipment is connecting The Children’s Institute with physicians, caregivers and school districts and supporting efforts that include Individualized Education Program conferences (IEPs) with school districts, foster parent support groups and informational sessions, and connecting various campuses of The Children’s Institute to share knowledge and collaborate.
CONCLUSION

The Children’s Institute has made every effort to ensure that as we defined and prioritized the significant health needs undertaken as strategic initiatives we were well-informed on the best ways to meet the needs. We solicited and took into account input we received from government health departments, representatives of the medically underserved, low-income and minority populations, and many other experts in the field of children with special healthcare needs.

This Community Health Needs Assessment report was adopted by The Children’s Institute’s Board of Directors on June 18, 2015. The implementation strategy for this reporting year will be finalized and released on November 15, 2015, in accordance with IRS Section 501(r).

This report is available on The Children’s Institute’s web site (www.amazingkids.org) and a paper copy of the report is available for public inspection upon request and without charge at our facility located at 1405 Shady Avenue, Pittsburgh, PA, 15217.