

ST. JUDE CHILDREN'S RESEARCH HOSPITAL

The mission of St. Jude Children's Research Hospital is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. Consistent with the vision of our founder Danny Thomas, no child is denied treatment based on race, religion or a family's ability to pay.

Community
Health
Needs
Assessment



Presented by
Tripp Umbach

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Introduction

The following report documents a Community Health Needs Assessment (CHNA) conducted by Tripp Umbach under the direction of leadership from St. Jude Children’s Research Hospital. This report fulfills the requirements of a new federal statute established within the Patient Protection and Affordable Care Act (PPACA) requiring that nonprofit hospitals conduct CHNAs every three years.

Consultant Qualifications

Tripp Umbach is a private healthcare consulting firm headquartered in Pittsburgh, Pennsylvania. Tripp Umbach is a recognized national leader in completing community health needs assessments, having conducted more than 250 community health needs assessments over the past 21 years. Today more than one in five Americans live in a community where Tripp Umbach has completed a community health assessment.

Paul Umbach, founder and president of Tripp Umbach, is among the most experienced community health planners in the United States, having directed projects in almost every state and internationally. Tripp Umbach has written two national guide books^{1,2} on the topic of community health and has given presentations at more than 50 state and national community health conferences.

About St. Jude Children’s Research Hospital

St. Jude is a specialty hospital that treats pediatric cancer and blood disorders. Patients at St. Jude are referred by a physician, diagnosed with a disease currently under study, and eligible for a research protocol. St. Jude is the only pediatric cancer research center where families never pay for treatment not covered by insurance. **In fact, no family ever pays St. Jude for anything.** Transportation, housing and food are among the no-cost services provided to ensure families coming to St. Jude can focus on their child. No child is ever denied treatment due to race, sex, nationality, ethnicity, religion, or the family’s ability to pay. More information is provided in the Community Definition section of this report.

¹ A Guide for Assessing and Improving Health Status Apple Book:

http://www.haponline.org/downloads/HAP_A_Guide_for_Assessing_and_Improving_Health_Status_Apple_Book_1993.pdf

² A Guide for Implementing Community Health Improvement Programs:

http://www.haponline.org/downloads/HAP_A_Guide_for_Implementing_Community_Health_Improvement_Programs_Apple_2_Book_1997.pdf

Project Overview

The CHNA process began in October 2012 and was completed by April 2013, in time to file the report with the St. Jude IRS submission for fiscal year 2012-2013.

The CHNA process included extensive input from persons who represented the broad interests of the communities served by the hospital, including those with special knowledge of public health issues.

Project Goals

This CHNA has three primary goals: to identify the health needs of special populations served by St. Jude, to develop a deeper understanding of these needs, and to guide development of an implementation strategy to address selected priority needs. St. Jude will develop an implementation plan to address those needs upon which it can have an impact, provide annual updates on progress toward meeting these needs, and conduct future needs assessments as required and directed by the IRS.

Methodology

Key data sources in the CHNA included:

- ❑ **Community Health Assessment Planning:** A series of meetings were held between Tripp Umbach associates and the St. Jude CHNA project team consisting of leadership from St. Jude Children's Research Hospital.
- ❑ **Secondary Data:** National, regional, and St. Jude hospital-specific data were gathered and analyzed for the purposes of the study. Examples of the national, secondary data sources used for this report include but are not limited to: the Centers for Disease Control, the Data Resource Center for Child and Adolescent Health, the Bureau of Labor Statistics, the Youth Risk Behavior Surveillance System, and Children with Special Health Care Needs. Secondary data assisted the CHNA process by providing a quantifiable understanding of the identified needs.
- ❑ **Interviews with Key Stakeholders:** Tripp Umbach worked closely with hospital leadership to identify leaders from organizations with special knowledge and/or expertise in public health and in specialty areas where St. Jude provides services. Such persons were interviewed as part of the needs assessment planning process. (See Appendix A for a list of Stakeholder Titles and Organizations)

- ❑ **Focus Groups with Relevant Committees:** Tripp Umbach worked closely with the hospital to identify groups with knowledge of specialized children’s health issues who could be represented in a focus group. St. Jude identified the Family Advisory Council³ and the Medical Executive Committee⁴ as groups with experience and understanding of children’s health nationally, regionally, and within St. Jude. Two focus groups were conducted with a total of approximately 50 participants.
- ❑ **Identification of top health needs:** Top health needs were identified by analyzing secondary data, stakeholder input and focus group input. Tripp Umbach prioritized the needs identified in the assessment based on analyses of secondary data, where available, and strong consensus among stakeholders and focus group participants.
- ❑ **Inventory of Resources:** Tripp Umbach completed an inventory of resources that are currently available nationally, regionally, and statewide to address the health needs identified by the CHNA. The inventory was conducted via internet research. More than 100 resources were inventoried with the capacity to meet the health needs identified in the St. Jude CHNA.
- ❑ **Prioritization and Implementation Planning:** St. Jude is developing an implementation plan for the prioritized needs that align with the hospital’s mission and vision. Tripp Umbach facilitated a work session with the St. Jude CHNA project team to address the following questions:
 - What is the magnitude of each need?
 - Which needs match the hospital’s strengths/expertise?
 - Can other organizations meet the need more effectively/efficiently, and if so, can a partnership be created?
 - What is St. Jude’s plan to address selected high-priority needs?

³The Family Advisory Council (FAC) is a council made up of parents working directly with hospital to foster mutually beneficial partnerships with patients, families and healthcare providers.

⁴The Medical Executive Committee (MEC) is the authoritative body empowered to act for the clinical staff in all matters in which the clinical staff are concerned.

Community Definition

St. Jude: Patient Population and Clinical Focus

The community served by St. Jude can best be defined by understanding its patient population and clinical focus. St. Jude is a specialty hospital that treats pediatric cancer and blood disorders. It serves as a national referral center for children with cancer as well as a local referral center for children with cancer, blood disorders, and HIV/AIDS. St. Jude does not admit children for any diagnostic groups outside of these services and does not offer medical services beyond those necessary to care for children with these diseases. St. Jude does not have an emergency room (ER). A referral from a medical professional external to St. Jude, typically the child's pediatrician or a pediatric subspecialist, is necessary prior to accepting a patient for treatment to St. Jude.

The dominant clinical focus of St. Jude is the treatment of pediatric cancer. St. Jude also serves as a primary hematology hospital for patients in the geographic area surrounding its main campus, with the largest program being treatment of sickle cell disease. Other hematological diseases include hemophilia and anemias. St. Jude also accepts pediatric patients with HIV/AIDS and serves as the area's primary provider for infants, children and adolescents with HIV infection.

St. Jude's primary clinical effort centers on providing ground-breaking, research-driven treatments. More specifically, about 7,800 active patients are seen at St. Jude yearly, most of who are enrolled on clinical trials for new treatments developed by St. Jude and who are treated on a continuous outpatient basis. The hospital has 78 beds for patients requiring hospitalization during treatment. It should be noted that St. Jude has developed unique resources that allow a significant portion of patients to be treated as outpatients who would be admitted into inpatient units at most hospitals. This is accomplished through patient housing dedicated solely to St. Jude patient families (capacity for 996 patients/family members) designed with infection control measures such as HEPA filtration, infection-resistant surfaces and other medical safeguards that are not available in hotels or patients' homes.

St. Jude has a network of six affiliated pediatric hematology/oncology clinics in the U.S., allowing St. Jude to extend care and benefits to more children and increase the number of children able to be treated on St. Jude clinical trials. St. Jude also operates an international outreach program aimed at sharing knowledge and resources to improve the survival rate of children with cancer worldwide. St. Jude has 20 international partner sites in 14 countries.

St. Jude is also a research organization, with research covering a broader scope of health issues than the diseases treated as a primary diagnosis. For the purposes of this report, the focus is solely on those diseases for which children are admitted to St. Jude for treatment.

Definition of Community and Rationale

Per the IRS-990 CHNA requirements, a hospital's community can be defined in many ways:

- Target population served (e.g., children, women, or the aged)
- Geographic location (e.g., a city, county, or metropolitan region)
- Principal function of the hospital (e.g., a particular specialty area or targeted disease)

For the purposes of this report, St. Jude has defined its community as 'Children with cancer nationwide, which includes U.S. territories, and primarily children in the geographic area with blood disorders and HIV/AIDS.'

This definition was guided by the fact that cancer treatment is the hospital's predominant focus (>70%), and the largest percentage of new cancer patients come from areas across the U.S. (Table 1).

The local market encompasses Memphis, Tennessee and the surrounding geographic area. Approximately 25% of new oncology patients reside within this area.

Table 1: New Cancer Patients FY12

Referral Area	Number of Patients	% of Total
Memphis, TN and Surrounding area	115	25
Affiliate Referral	159	34
National Referral (other areas of U.S.)	176	38
International Referral	13	3
Total	463	100

Source: St. Jude Referring Physicians Office

Community Health Needs Assessment

The CHNA resulted in the identification of four national pediatric health needs that are broader and more far-reaching than those faced by our defined population of pediatric patients.

National pediatric health needs that were identified in this assessment include:

- 1) Improving access to healthcare services
- 2) Improving coordination of care
- 3) Improving child health status through behavioral modification
- 4) Improving access to mental health services

Where appropriate and practical, Tripp Umbach attempted to align broad national pediatric needs with diseases and services that could reasonably be provided by St. Jude, given the hospital's specialized focus. For example, there are multiple issues with quality of care when children move from specialized pediatric facilities to more general community healthcare settings; this is especially the case when children are transferred from highly specialized, intensive research facilities such as St. Jude.

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NEED 1: IMPROVING ACCESS TO HEALTHCARE SERVICES

Statement of Need

The top-priority need identified by the CHNA is improved access to healthcare services. This need encompasses several areas of concern, including improving access to affordable health insurance coverage, improving access to preventive healthcare and education, and addressing the shortage of pediatric specialty healthcare providers.

Support for Need

Consensus among stakeholders and focus group participants, as well as secondary data analyses, support the conclusion that despite the existence of medical resources and healthcare facilities, access to healthcare resources may be limited. Contributing factors include inadequate health insurance coverage and a shortage of specialty providers, particularly for individuals who reside in more rural areas and/or are under/uninsured.

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Supporting Data and Key Discussion Points

Inadequate Insurance Coverage:

- The CDC reports that in 2011, 7.0% of U.S. children under the age of 18 (equivalent to 5.2 million children) were uninsured at the time of interview.⁵ This rate has been declining for the past seven years and is one of the lowest rates of uninsured for a specific age group. However, rates can vary considerably among different populations. For example:
 - American Indian and Alaska Native children show the highest uninsured rate compared with other racial categories in the U.S. (24.8% compared to 5.8%-7.9% for other races).⁶ Hispanic children show more than double the rate of being uninsured than non-Hispanic children (12.9% vs. 5.3% respectively).⁶
 - Children not living in a Metropolitan Statistical Area (MSA) report higher uninsured rates than children in small or large MSAs.⁶
 - For the 10-state region closest to St. Jude, Florida shows the highest rates of children both 0-5 yrs. and 6-17 yrs. that do not have health insurance (in 2010, 13% and 16% respectively).
 - The highest rate of uninsured patients at St. Jude occurs for those with a diagnosis of HIV/AIDS; 32.6% of these patients are uninsured.
- Stakeholders and focus group participants discussed several concerns related to inadequate insurance coverage.
 - Among these concerns was the gap between the income qualifications for state-funded health insurance and the ability of residents to afford private-pay health insurance premiums. Participants reported that health insurance can be unaffordable, leading residents to be underinsured with limited coverage and high deductibles or uninsured with no coverage at all.
 - Stakeholders and focus group participants noted that state-funded health insurance is not readily accepted in all areas, causing residents to travel lengthy distances and/or wait lengthy periods to receive health services.
 - Employer-provided benefits were also discussed. Participants noted that not all employers are able to offer comprehensive health insurance benefits due to the high cost of premiums; some employees opt out of healthcare plans offered by employers; or employers hire part-time employees only.

⁵ Early Release of Selected Estimates Based on Data from the 2011 National Health Interview Survey.

⁶ Summary Health Statistics for U.S. Children: National Health Interview Survey, 2011. CDC. Series 10, Number 254. December 2012.

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- Finally, stakeholders working in research-related environments discussed how considerations related to health insurance affect individuals' ability to participate in important clinical trials.
- Of note, a child being uninsured may not be the only contributing factor in a child not receiving care; an uninsured caregiver, language or cultural barriers, or lack of other resources (i.e., money, time, transportation, etc.) may all contribute as well.

Cost as a Barrier to Receiving Healthcare:

- From 2005 to 2010, the United States witnessed a steady rise in the rate of persons who failed to obtain needed medical care due to cost sometime in the 12 months prior to the survey (from 5.3% in 2005 to 6.9% in 2010). In 2011 there was a slight decline to 6.5%.⁵
 - The rates for children are the lowest for any age range; 1.7% of children under age 18 needed but did not receive care due to cost in 2011.⁵
 - Children living in a home in which the parents earn less than \$35,000 show the highest rate of having unmet medical needs due to cost (2.9%, or approximately 645,000 children).⁶
 - Approximately 3.3% of children (more than 2.4 million children) were reported to have delayed care due to cost.⁶
- It was noted that some insurance plans have restrictions and at times co-pays can be too costly for residents to afford. The inability to pay leads some residents to avoid or delay required medical care including follow-up appointments after ER visits and failure to take prescription medicines.

Lack of a Regular Place for Healthcare:

- Between 1997 and 2011, the year 2010 showed the lowest rate of individuals (of all ages) with a usual place to go for medical care (85.4%); 2011 showed a slight rise to 86.8%.⁵ This rate varied among populations depending on various factors.
 - In 2011, nearly all children (<18 yrs. of age) in the U.S. had a usual place of healthcare (96.7%).⁶
 - Uninsured children show the highest rate of not having a usual place of healthcare (23.7%) whereas children with private insurance show the lowest rate (1.3%).⁶
 - Of children without a usual place of healthcare, some populations showed higher rates compared to their counterparts, including those aged 12-17 yrs., those who are Native Hawaiian or Other Pacific Islander, those with a father and no mother, and those with parents with less than a high school education.⁶

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- Across all demographic classifications (i.e., age, gender, race, income, etc.), the most popular place for healthcare is a child's doctor's office. Children from lower-income households (i.e., < \$35,000 annual income) go to a clinic for their usual healthcare more often than children from higher-income households.⁶

Time since Last Contact with Healthcare Professional:

- U.S. children aged 12-17 (compared with ages 0-4 and 5-11 yrs.) show the highest rate of going more than five years since seeing a healthcare professional (1.7%).⁶
 - Hispanic children show nearly four times the rate of not going to a healthcare professional in five years or more as compared with non-Hispanic children (3.7% and 1.0% respectively).⁶
 - Children whose parents have less than a high school diploma show almost five times the likelihood of not seeing a healthcare professional in the past five years (4.7%) as compared with children with parents with a high school diploma or higher.⁶
- More than one in every six children in Mississippi has not gone to a preventive healthcare appointment in the past year.

Overuse of the ER for General Healthcare Needs:

- In 2011, nearly 6% of children went to an ER twice or more in the 12 months prior to the survey.⁶
 - The youngest children (ages 0-4) showed the highest rates of ER visits (8.8% children age 0-4 visited an ER twice or more in the 12 months prior to the survey).⁶
 - Children in households with an annual income of less than \$35,000 showed more than double the rate of two or more ER visits in one year as compared with children in households with an annual income of \$35,000 or more (9.6%).⁶
- Key stakeholders and focus group participants discussed overuse of hospital ERs for non-emergent services for common childhood ailments (i.e., colds or other minor injuries/illnesses) that would generally be treated at a healthcare clinic or a primary care physician's office.
 - Participants felt potential reasons for individuals' overuse of ERs may be lack of preventive care education, demographics, and/or cultural differences.
 - Focus group participants expressed concern that when caregivers choose to go to an ER rather than a pediatrician, follow-up care can be minimal or non-existent. This scenario may additionally lead to insufficient understanding of how and when to take medications.

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Need to Improve Education, Training, and Availability of Healthcare Professionals:

- According to the National Resident Matching Program (NRMP), across the U.S., just over half (58.9% in 2012) of the available positions in Pediatric Hematology/Oncology were filled. In other words, in 2012, of 158 job openings in Pediatric Hematology/Oncology, 65 positions went unfilled (Table 2).
 - This trend has improved since 2009, but has remained relatively stable between the years of 2010 and 2012 (only 53.5% of the positions were filled in 2009 compared to 60.3% in 2010 and 58.6% in 2011).

Table 2: Pediatric Job Openings and % Filled Per Year (2009-2012)

Pediatrics	2012			2011			2010			2009		
	No of Positions	% Filled		No of Positions	% Filled		No of Positions	% Filled		No of Positions	% Filled	
		U.S.	Total									
Developmental and Behavioral Pediatrics	32	43.8	65.6	32	40.6	78.1	-	-	-	-	-	-
Neonatal-Perinatal Medicine	222	50.9	85.6	223	47.1	83.4	221	44.3	76.5	208	48.1	76.9
Pediatric Cardiology	127	62.2	92.9	124	68.5	99.2	118	71.2	99.2	108	70.4	96.3
Pediatric Critical Care Medicine	152	50.7	86.8	150	47.3	77.3	139	49.6	75.5	141	47.5	78.0
Pediatric Emergency Medicine	151	62.3	94.0	136	72.1	92.6	134	71.6	89.6	118	66.1	92.4
Pediatric Gastroenterology	74	68.9	98.6	72	61.1	94.4	63	57.1	88.9	60	63.3	93.3
Pediatric Hematology/Oncology	158	58.9	90.5	152	58.6	87.5	146	60.3	90.4	142	53.5	86.6
Pediatric Nephrology	47	40.4	66.0	51	23.5	56.9	50	32.0	62.0	-	-	-
Pediatric Pulmonology	63	36.5	66.7	56	41.1	60.7	54	44.4	75.9	-	-	-
Pediatric Rheumatology	27	40.7	55.6	27	33.3	51.9	24	37.5	54.2	22	45.5	77.3
Pediatric Sports Medicine	17	70.6	88.2	14	64.3	100.0	11	72.7	100.0	12	58.3	100.0

Source: National Resident Matching Program

- The U.S. Bureau of Labor Statistics predicts that employment for all physicians and surgeons, including pediatric oncologists, will grow 22% over the decade between 2008 and 2018.⁷ This projected growth is much faster than the average for all occupations.
 - One contributing factor to the expected high demand for new physicians is the large number of physicians expected to retire between 2008 and 2018.
 - However, new technologies may enable physicians to be more productive, thus tempering the demand for new physicians. The increased use of physician assistants and nurse practitioners due to rising healthcare costs may also potentially lessen the need for new physicians.

⁷ Pediatric Oncologist: Job Description, Duties and Outlook. Education Portal. http://education-portal.com/articles/Pediatric_Oncologist_Job_Description_Duties_and_Outlook.html

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- Stakeholders and focus group participants expressed a strong concern that the shortage of trained pediatric specialists represents a growing national trend that will increasingly impact the health of children. Increasing the pediatric primary care workforce available to provide clinical care and services would better serve underserved populations, potentially lowering ER utilization costs and promoting better management and/or prevention of increasingly prevalent chronic diseases.
 - Focus group participants mentioned that obtaining appointments in a timely manner for general, primary or pediatric specialty care can be a major obstacle for children's health.
 - Stakeholders mentioned that caregivers of oncology patients face additional challenges of accessing primary and/or specialty providers within their community who are appropriately educated and prepared to provide required pediatric services, including new or experimental treatments. Focus group participants felt that, while there are substantial continuing medical education efforts for St. Jude physicians and health professionals as well as the community, increased education efforts could be an added advantage to St. Jude and its patients.
- Stakeholders mentioned that more online tools and increased training opportunities with peers could improve the connections between providers and lead to more accurate diagnoses.
- Focus group participants held the opinion that some healthcare professionals, such as home health nurses, are not trained in effective communication of follow-up plans, medication plans, and other issues.
 - Participants discussed concerns about the level of understanding of prescribed medications, noting a strong connection between understanding level and preventive care education.

NEED 2: IMPROVING COORDINATION OF CARE

Statement of Need

The second-priority need identified by the CHNA is to improve coordination of care and communication among healthcare and non-healthcare providers and agencies.

Support for Need

Stakeholders and focus group participants expressed shared concerns regarding the need to improve coordination of care. Stakeholders and focus group participants agree that the creation of an innovative system of care that promotes collaboration and appropriate distribution of resources is needed. Also, participants discussed the

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differences in access to healthcare options for patients at St. Jude versus patients who have transitioned to care outside of St. Jude. Participants also recognized challenges in accessing transitional healthcare services that facilitate the leap from St. Jude to adult-care facilities.

Supporting Data and Key Discussion Points

- Stakeholders and focus group participants were concerned with the current level of coordination offered by healthcare providers, especially in relation to pediatric services (in a general sense unrelated to experiences at St. Jude).
- Stakeholders also discussed that many existing organizations while well-meaning, have a very poor coordination/collaboration system that prohibits them from providing resources to patients and/or the community they serve.
 - For example, most communities have foundations aimed at improving the health of children, but these often lack connection to child advocacy programs that collaborate with children's hospitals.
- Stakeholders implied there may be limited communication between patients and healthcare providers, specifically in reference to language barriers.
- As noted in the previous section, stakeholders felt that caregivers of oncology patients face additional challenges of accessing primary and/or specialty care providers who are appropriately educated and prepared to provide pediatric services within their community.
- Focus group participants mentioned a lack of communication and/or coordination of care between some pediatric primary care providers and oncologists. Participants indicated that the lack of collaboration among providers can lead to a disjointed network of providers ultimately causing a disorganized and cumbersome referral process.
- Participants also discussed concerns related to tracking survivorship and assessing needs of St. Jude patients after they are discharged.

NEED 3: IMPROVING CHILD HEALTH STATUS THROUGH BEHAVIORAL MODIFICATION

Statement of Need

The third need identified by the CHNA is to improve access to preventive education and care in order to improve child health status.

Support for Need

Focus group participants expressed the strong opinion that behavioral health can be linked to many of the future health problems of children after discharge from St. Jude. Participants unanimously agreed that St. Jude provides a very positive source of information and directs patients and their families to external resources to assist with care. However, they noted that in the vast majority of communities across the nation, organizations are often not as comprehensive at informing individuals of all available healthcare resources due to lack of internal resources and funding restrictions.

Supporting Data and Key Discussion Points

Socioeconomic Barriers:

- Participants noted the additional challenge of achieving clear understanding of any provided information and materials by individuals of different education levels and cultural backgrounds.
- Participants felt that individuals may not always be aware of healthy choices due to cultural norms, limited access to preventive healthcare, limited prevention education, and community outreach in some areas.

Unhealthy Lifestyle Choices:

- Stakeholders and focus group participants believed that poor lifestyles choices may negatively affect individual health status, and consequently, cause an increase in the consumption of healthcare resources.
 - Specifically, lifestyle choices such as poor nutrition, inactivity, smoking, and abuse of alcohol and other drugs can lead to chronic illnesses such as obesity, diabetes, and pulmonary diseases.
 - Participants believed that individuals making such lifestyle choices may lack the awareness, motivation and/or access to options to implement healthy behaviors.
- Stakeholders noted that poor health during childhood is strongly tied to the onset of various diseases in adulthood and can further impact children being treated for life-threatening diseases.

Unhealthy Eating Habits in Children⁸:

- The CDC reports that most children and adolescents in the U.S.:
 - Do not eat the recommended 2½ to 6½ cups of fruits and vegetables a day.
 - Do not eat the recommended 2-3 ounces of whole grains a day.
 - Consume much more than the recommended 1,500-2,300 mg of sodium a day.
- Stakeholders and focus group participants noted that whereas some residents may be aware of and motivated to make healthy choices, healthy options may not be available in some communities or affordable for some residents.
 - Specifically, focus group participants observed that less healthy food is more readily available than healthier options and a majority of school systems do not offer healthy food choices.

Inadequate Physical Activity in Children⁹:

- The CDC recommends that children between the ages of 6 and 17 get at least 60 minutes of physical exercise per day.
 - A 2011 study found that only 29% of high school students reported getting the recommended 60 minutes of physical activity per day for all seven days prior to the survey.

Increased Childhood Obesity¹⁰:

- The CDC reports that in the past 30 years, obesity has more than doubled for children and tripled for adolescents.
 - The obesity rate in U.S. children aged 6-11 years old has risen substantially, from 7% in 1980 to 18% in 2010. Similarly, in adolescents aged 12-19 the obesity rate has risen from 5% to 18%.
 - Approximately one in three children is either overweight (BMI between the 85th and 95th percentile for that age) or obese (BMI above the 95th percentile for that age).
 - Obese children have increased risk for health conditions including bone and joint problems, sleep apnea, heart disease, type 2 diabetes, stroke, and osteoarthritis, as well as social and psychological problems such as stigmatization and poor self-esteem.

⁸ Adolescent and School Health. CDC. <http://www.cdc.gov/healthyyouth/index.htm>

⁹ Physical Activity Facts. CDC. <http://www.cdc.gov/healthyyouth/physicalactivity/facts.htm>

¹⁰ Childhood Obesity Facts. CDC. <http://www.cdc.gov/healthyyouth/obesity/facts.htm>

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- Children who are overweight or obese are also at an increased risk for many types of cancer, including cancers of the breast, colon, endometrium, esophagus, kidney, pancreas, gall bladder, thyroid, ovary, cervix, and prostate, as well as multiple myeloma and Hodgkin lymphoma.

Increased Diabetes in Children:

- The prevalence of diabetes in U.S. children is increasing.
 - More children than ever before are being diagnosed with pre-diabetes (e.g., blood glucose levels at a high enough level to put the child at risk for diabetes) and type 2 diabetes.¹¹
 - The prevalence of type 1 diabetes in children (aged 0-19) is 1.7 for every 1,000 children.¹³The SEARCH for Diabetes in Youth Study found that although type 1 diabetes is more prevalent than type 2 diabetes for children under age 10, the rate of type 2 diabetes rises dramatically after age 10.¹²
 - The SEARCH study also showed that type 1 diabetes is most prevalent in Non-Hispanic, white children under the age of 10, and type 2 diabetes is most prevalent in American Indian children between the ages of 10-19.¹³
- Stakeholders noted that the increasing rates of obesity and diabetes in adults and children are among the top health concerns for children nationally.
- Focus group participants believed that obese and pre/diabetic individuals are not always receiving the preventive care and screenings required to manage health-related issues due to a variety of barriers including health insurance restrictions; limited availability of preventive resources/programs; and an overall lack of knowledge of primary prevention and healthy living behaviors.

Sexual Risk Behaviors in High School Students:

- The Youth Risk Behavior Surveillance System 2011 Survey for the 10-state region closest to St. Jude reports:
 - Louisiana shows the highest rates of students who report not having been taught about HIV/AIDS in school (i.e., more than one in four).
 - More than 30% of high school males in Mississippi report having had sexual intercourse with four or more persons.

¹¹ Children and Diabetes – More Information. Diabetes Public Health Resource. CDC.
<http://www.cdc.gov/diabetes/projects/cda2.htm>

¹² 2011 National Diabetes Factsheet. Diabetes Public Health Resource. CDC.
<http://www.cdc.gov/diabetes/pubs/factsheet11.htm>

¹³ Ibid.

- Alabama and Mississippi show the highest rates of many sexual risk behaviors; however, Missouri and Florida show the highest rates for sexual activity involving alcohol and drug use (23.5% and 23.3%, respectively).
- More than 50% of sexually active females in Kentucky, Arkansas, and Alabama report not using a condom the last time they had sexual intercourse. Unprotected sexual intercourse is a major risk behavior linked to the contraction of HIV/AIDS.

NEED 4: IMPROVED ACCESS TO MENTAL HEALTH SERVICES

Statement of Need

The fourth need identified by the CHNA is improved access to mental health services.

Support for Need

Stakeholders believed that there is a need for increased access to mental health services and resources specific to children.

Stakeholders and focus group participants believed that existing mental health services have limited capacity to meet the demand for services due to recent closures and funding cuts, which are occurring on a national and regional level. Furthermore, participants believed many healthcare plans are cutting mental health coverage for adults and possibly children.

Specifically, participants cited the limited availability of pediatric mental health services and psychological/psychiatric specialists, noting that general practitioners are not always prepared to manage mental health diagnoses and treatment. Thus, it may be difficult to find specialized healthcare professionals to treat mental health issues in a child with an existing disease.

Participants also expressed the view that mental health services are disjointed and at times difficult to navigate.

Supporting Data and Key Discussion Points

Mental Illness in Children¹⁴:

- Of youth aged 8-15 yrs., approximately 13% live with a mental illness that is severe enough to impair daily life. In 13-18 year olds, the rate rises to 21%.
 - The average amount of time between the initiation of mental illness symptoms and receiving care is 8 to 10 years.
 - Across the U.S., it is reported that only 20% of children with mental illness are treated.
 - Suicide is the third leading cause of death for youth aged 15-24 yrs. (9.7 per 100,000 deaths in 2009).

Autism¹⁵:

- As many as 14 of every 10,000 children may have autism or a related condition.
 - Autism not only affects the child, it also affects their families. Approximately 125,000 Americans are affected by autism or related disorders.
 - Having more than one child with autism is not uncommon; approximately 4,000 families in the U.S. have two or more children with autism.
 - Boys are approximately three times more likely than girls to have autism.

Depression¹⁶:

- FDA warnings were updated for children's depression medications in 2007. However, according to a study of community-based pediatric practices, few individuals/practices changed their monitoring of a child's response to depression medication as recommended by the FDA.
 - This observation may prompt concerns about the responsiveness of medical professionals to the idiosyncrasies of child mental health issues.

¹⁴ Improving Lives, Avoiding Tragedies. Children's Mental Health Fact Sheet. Mental Health America.

¹⁵ Autism, Children's Mental Health, Mental Health Info. Mental Health America.

<http://www.mentalhealthamerica.net/farcry/go/information/get-info/children-s-mental-health/autism>

¹⁶ Richardson, L.P., Lewis, C.W., Casey-Goldstein, et. al. Pediatric primary care providers and adolescent depression: a qualitative study of barriers to treatment and the effect of the black box warning. Journal of Adolescent Health. 2007 May; 40(5).

Assessment of total community health needs

Inadequate Funding for Mental Health Services¹⁷:

- The National Alliance on Mental Illness reported that in Illinois alone, funding for mental health was reduced by \$114 million between the years of 2009-2011; nationwide nearly \$1.8 billion has been cut for mental health since 2009.
 - Ramifications of cutting mental health funding are far-reaching. For example, individuals with untreated mental illness are forced into higher-cost settings such as ERs, causing over-population of the ERs; ER doctors may not be able to adequately treat mental health issues; and increasing numbers of untreated individuals in a community may cause safety concerns.
- It is estimated that only 50% of individuals needing mental health treatment receive it, potentially due to lack of access or personal choice not to pursue care.
- The closing of many mental health facilities/programs (i.e., public psychiatric units or substance abuse programs) in Pennsylvania, New Jersey, Mississippi, and Indiana has been noteworthy as well.

¹⁷ Thomas, Monifa. States make deep cuts in mental health funding. Chicago Sun-Times.
<http://www.suntimes.com/news/metro/4224421-418/states-make-deep-cuts-in-mental-health-funding.html>

Appendix A

Key Stakeholder Organizations

Representatives (i.e., Chair of Board of Directors; Deputy Commissioner for Improvement and Training; Senior VP of Special Initiatives; Director of Social Worker; Senior Investigator; Professor of Department of Biopharmaceutical Sciences/Pharmaceutical Chemistry; Professor of Pediatrics; Assistant Chancellor for Personalized Medicine; Professor of Department of Medicine in Hematology/Oncology; Medical Monitor/Study Director; Director at Institute for IPIT; Chief Executive Officer of Pharmaceutical Science Research Program; Member of TN Cancer Coalition; Pediatric Chair of East TN State University; Administrator/Chief Nursing Officer; Medical Director; Chief Academic/Administrator Officer; Clinical Director; CEO; Associate Director/Director of Psychological Services in Cancer Survivorship; and Senior Professor) from the following organizations provided detailed input during the community health needs assessment process:

- The St. Jude Affiliate Clinic at Huntsville, AL: Hospital for Women and Children
- Department of Pediatrics for the University of Tennessee Health Science Center
- Ryan White Program
- University of Tennessee Health Science Center College of Medicine
- Methodist Affiliated Services' Home Care, Hospice and Palliative Services
- American Society for Clinical Pharmacology and Therapeutics
- Departments of Biopharmaceutical Sciences and Pharmaceutical Chemistry, UCSF
- Vanderbilt University School of Medicine
- Department of Medicine, Section of Hematology/Oncology, Cancer Research Center, University of Chicago
- Comprehensive Sickle Cell Center/Benign Hematology, Methodist University Hospital
- Methodist University young adult transition unit
- University of Michigan: Specialty: Pediatric Hematology/Oncology
- Tennessee Cancer Coalition (TC2)
- The St. Jude Affiliate Clinic in Johnson City, TN
- Bristol Meyers Medical Monitor
- The Henry J. Kaiser Family Foundation
- The West Clinic, Memphis, TN
- Children's Hospital of Illinois
- Le Bonheur Children's Medical Center
- Sarrouf Law, LLP
- State of Tennessee Department of Health
- St. Jude Children's Research Hospital