

Texas Scottish Rite Hospital for Children
Community Health Needs Assessment





Texas Scottish Rite Hospital for Children • 2222 Welborn Street • Dallas, TX 75219

Name: Texas Scottish Rite Hospital for Crippled Children
dba Texas Scottish Rite Hospital for Children (TSRHC)

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A copy of this written report is available for public inspection without charge at Texas Scottish Rite Hospital for Children.

Contact: Neil Devroy
Sr. Director of Communications, Public Relations
neil.devroy@tsrh.org
214-559-7653

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I. INTRODUCTION



A. About Texas Scottish Rite Hospital for Children (TSRHC)

TSRHC is a pediatric specialty hospital located in Dallas, Texas. TSRHC provides ambulatory and inpatient care to children from birth up to 18 years of age. Since its founding in 1921 as a Masonic charity, TSRHC has provided treatment free of charge. The hospital began accepting reimbursement for patient care in October 2012. **However, the hospital's mission has not changed – TSRHC continues to provide the highest quality care available for children, within its scope of services, regardless of the family's ability to pay.**

TSRHC provides a financial assistance program for those families without insurance or who are not able to pay. Families that meet the eligibility criteria may qualify for free or discounted care.

TSRHC practice areas include pediatric orthopedics, neurology conditions related to orthopedic diagnoses, rheumatology, developmental disabilities, dyslexia, and other learning problems related to reading, writing and mathematics (See pages 7-11 and Appendix 1, page 22, for Pediatric Orthopedic and other medical services provided by TSRHC).

As a pediatric specialty hospital, TSRHC is a unique resource benefiting children with disabilities and other orthopedic needs and their families in Texas through clinical care, education and research. The hospital is one of two specialty providers of pediatric orthopedics and related neurological disorders located in the state and the only one located in northeast Texas. TSRHC is responsible for providing premier care to more than 18,000 patients and their families annually.

B. TSRHC Mission Statement:

Our Core Values

Dedicated to the health and happiness of children, we will be guided by what is best for the child, in keeping with the following values:

LEGACY

We will preserve and perpetuate our heritage and the principles of Freemasonry by reaching out to others in need of our services.

INTEGRITY

We will protect our reputation for excellence by setting high standards and to consistently meet them.

RESPECT

We believe that every person is worthy of respect. We will treat others as we would like to be treated, with honesty and compassion; being sensitive to them and accepting of their differences.

FAMILY-CENTERED

We believe that the needs of children must be considered in the context of their families and encourage family involvement in decisions regarding each child's care.

QUALITY

We take pride in the quality of patient care and support services we provide. We strive to continuously improve that quality by involving staff in problem-solving and encouraging innovation.

STEWARDSHIP

We will be diligent stewards of our resources:

People will be provided a respectful, stimulating and rewarding professional environment. Monetary gifts and assets entrusted to us by our donors will be used wisely to help children. Buildings and land will be kept clean, in good repair, and will be updated as needed to better meet the needs of the children we treat.

LEARNING

We strive to expand and share knowledge regarding the care of our patients through research, education and outreach programs.

C. CHNA Requirements

The following report documents a Community Health Needs Assessment (CHNA) conducted by the Dallas-Fort Worth Hospital Council Education & Research Foundation (DFWHCF) with the direction of the leadership team at Texas Scottish Rite Hospital for Children. Specifically, this CHNA is being conducted to comply with the federal tax law requirements implemented under the Patient Protection and Affordable Care Act (PPACA) of 2010 and set forth in Internal Revenue Code section 501 (r) requiring hospital facilities owned and operated by an organization described in Code section 501(c)(3) to conduct a community health needs assessment at least once every three years.

TSRHC relied on the guidance provided in Notice 2011-52 regarding conducting the CHNA for the hospital, which includes:

1. **Describing the community served** and how it was determined;
2. **Describing the process and methods used** to conduct the assessment, including sources of data and other information used in the assessment and analysis of community health needs;
3. **Describing how the hospital organization considered input** from persons with a broad interest of the community served;
4. **Providing prioritized description of all significant community health needs** identified and the process used; and
5. **Describing existing health care facilities and other resources** available to meet the community needs identified.

Through the assessment, TSRHC must evaluate the existing health care landscape of its community through an organized and reputable process as it relates to the scope of services provided. A planning team comprised of TSRHC executive leadership and DFWHCF research staff led the CHNA effort. The team worked together to define the community, identify and prioritize needs, and develop strategies that best address the health needs of the community as they relate to the scope of services provided at TSRHC. The required Written Implementation Strategy is set forth in a separate written document.

II. TSRHC COMMUNITY DEFINITION

For purposes of this CHNA Report, the TSRHC community is defined by reference to our target population and principal functions, to mean supporting patients and families requiring pediatric orthopedic services, in Northeast Texas as described below.

A. Patient Population



The community served by TSRHC can best be defined by understanding its patient population and clinical focus. TSRHC is a 501 (c)(3) specialty hospital located in Dallas Texas, which treats pediatric orthopedic and related neurological disorders. TSRHC provides premiere pediatric orthopedic and dyslexia services for children from birth up to 18 years of age who offer hope of improvement through the services provided by the hospital. Access to services is by physician referral.

Medical care is provided to children with orthopedic and related conditions not treated at other medical facilities. Many providers at TSRHC receive referrals from physicians and children's hospitals in the primary service area because the patient's condition

is either too acute or in some cases, so rare, the referring facility does not have adequately trained or experienced staff to provide the necessary care.

The hospital has a process to determine if TSRHC is the appropriate facility to meet a child's clinical needs. The process begins with a telephone or other referral from a physician or an application for services. An internal mechanism is utilized to determine if TSRHC can appropriately meet the needs of the patient through one of its service lines when the child's diagnosis is not a clear cut orthopedic condition. When TSRHC is unable to provide services, TSRHC, as part of its care coordination services, identifies referral resources that are provided to the family (See Section V, pages 18 – 21).

B. Pediatric Orthopedic Services:

In addition to general pediatric orthopaedic services, the pediatric orthopedic services for which patients are primarily referred to TSRHC are set forth below (See Appendix 1, page 22, for additional Medical Services provided by TSRHC).

Scoliosis and Spine Disorders



Scoliosis is a progressive condition causing the spine to curve or twist into a “C” or “S” shape. Signs and symptoms of scoliosis include uneven shoulders, a prominence of the shoulder blade and waistline discrepancies.

As reported by the Texas Department of State Health Services, idiopathic scoliosis occurs in 2-3% of the adolescent population.¹ Scoliosis affects 5 – 7 million people in the United States and can begin at any age, but most often develops in adolescents ages 10 – 15. The term "idiopathic" means unknown cause. Although the causes of the majority of scoliosis cases (80 - 85%) are not known, it tends to run in families. In childhood, idiopathic scoliosis occurs in both girls and boys. However, as children enter adolescence, scoliosis in girls is five to eight times more likely to increase in size and require treatment. Progression is most common during the growing years.²

Clubfoot and Other Foot Disorders

Clubfoot is a congenital deformity in which the foot is severely turned inward and pointed downward. It is one of the most common pediatric musculoskeletal conditions requiring referral to a pediatric orthopedic surgeon. The diagnosis is most often made at birth based upon the position and rigidity of the foot, though children are frequently diagnosed before birth by prenatal ultrasound.

TSRHC provides care to pediatric patients suffering from clubfoot and other foot disorders such as flat feet (Pes Planus), extra toes, toe deformities, tarsal coalitions, high arched feet (Pes Cavus), congenital vertical talus and metatarsus adductus. Idiopathic Talipes Equinovarus (ITEV) is the most common form of clubfoot and has a birth prevalence of 1/1000 births in Texas.³

¹ Texas Department of State Health Services, Spinal Screening Guidelines (<http://www.dshs.tx.us/spinal/spinalguide.shtm>).

² National Scoliosis Foundation (<http://www.scoliosis.org/info.php>).

³ Pubmed, Idiopathic talipes equinovarus (ITEV) (clubfeet) in Texas by R. N. Moorthi et. al. [<http://www.ncbi.nlm.nih.gov/pubmed/15633175>].

Nationally the prevalence of ITEV is 0.74/1000 live births, establishing that a disproportionate number of Texans are impacted by this disorder.⁴

Table 1: Prevalence of Clubfoot in Texas⁵

Race/Ethnicity	Rate (live births)
Overall	1.29/1000
Non-Hispanic Whites	1.38/1000
Hispanics	1.30/1000
Blacks	1.14/1000

Reduction Defects (Limb Lengthening)

Reduction defects of the upper and lower limbs affect approximately 75 children each year in Texas.⁶ According to the CDC, in the U.S. reduction deformity of the upper limbs occurs at a rate of 1 in 2,869 while reduction deformity in lower limbs occurs at a rate of 1 in 5,949. This is an estimated annual case count of 1,454 and 701, respectively. These conditions may be present at birth or could develop during childhood. Limb lengthening (including lengthening bones, replacing missing bone or correcting deformities in bone structure) is a surgical procedure used to correct deformities associated with these conditions. Infants of non-Hispanic black mothers have a higher prevalence of lower limb reduction defects at birth.⁷

Hand and Upper Limb Disorders



Hand disorders may include those present at birth as well as those resulting from trauma or are related to other conditions such as nerve injuries. Congenital (a condition present at birth) conditions like extra fingers (polydactyly), webbed fingers (syndactyly), missing fingers (symbrachydactyly), abnormal thumbs, and limited movement of stiff joints (arthrogryposis, as well as all types of congenital deformities of the hand are just some of the hand disabilities treated at TSRHC.

⁴ Medscape [<http://emedicine.medscape.com/article/1237077-overview>].

⁵ Medscape [<http://emedicine.medscape.com/article/1237077-overview>].

⁶ Texas Department of State Health Services Birth Defects Statistics (<http://www.dshs.state.tx.us/birthdefects/default.shtm>).

⁷ CDC Birth Defects Surveillance Data and Statistics (<http://www.cdc.gov/ncbddd/birthdefects/data.html>).

In the U.S., polydactyly occurs in 1/500 newborns and equally impacts boys and girls. African Americans are more likely to have polydactyly of the little finger while Whites and Asians are more likely to have polydactyly on the thumb side of the hand.⁸ Syndactyly is the most common of all congenital hand deformities with an incidence of around 1/2000 live births. Syndactyly is twice as common in white males as in any other pediatric group.⁹ The physicians at TSRHC treat numerous hand and upper body conditions, both congenital and those requiring complex reconstruction following trauma, in addition to hand disorders related to neurological conditions or nerve injuries. Examples of these complex problems include: nerve and skeletal injuries, limb disorders due to cerebral palsy, growth disorders in the upper limb and juvenile arthritis.

TSRHC also treats other conditions such as growth problems in the upper limb - e.g. after trauma to the growth plate, crooked limbs, tumors and tumorous conditions in the upper limb - lumps and bumps other than ganglions, bone and soft tissue. TSRHC also treats vascular problems, including malformations and tumors.

Hip Disorders

There are many forms of hip disorders such as developmental dysplasia of the hip, Legg-Perthes, and Slipped Capital Femoral Epiphysis (SCFE). Legg-Perthes, or Legg-Calvé-Perthes disease, is a condition where blood flow to the hip is compromised, and the ball at the top of the thighbone is injured temporarily. Legg-Perthes can cause pain in the hip and typically develops in children 4 – 9 years of age.

Some hip disorders are congenital while others develop as a result of an injury or other condition. For many the cause is unknown. Individuals at increased risk for hip dysplasia are Native Americans followed by African Americans and Asians.¹⁰ Individuals with a family history of developmental hip dysplasia are 10 times more likely to experience the condition than those without a history of the condition. Approximately 1 out of every 20 full-term babies has some hip instability and almost 3 out of every 1,000 will require treatment.¹¹

⁸ Boston Children's Hospital [<http://www.childrenshospital.org/az/Site1073/mainpageS1073P0.html>].

⁹ Pubmed Central (PMC), The Epidemiology, Genetics and Future Management of Syndactyly by D. Jordan et. al. [<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3308320/>].

¹⁰ MDGuidelines Medical Disability Advisor (<http://www.mdguidelines.com/hip-dysplasia>).

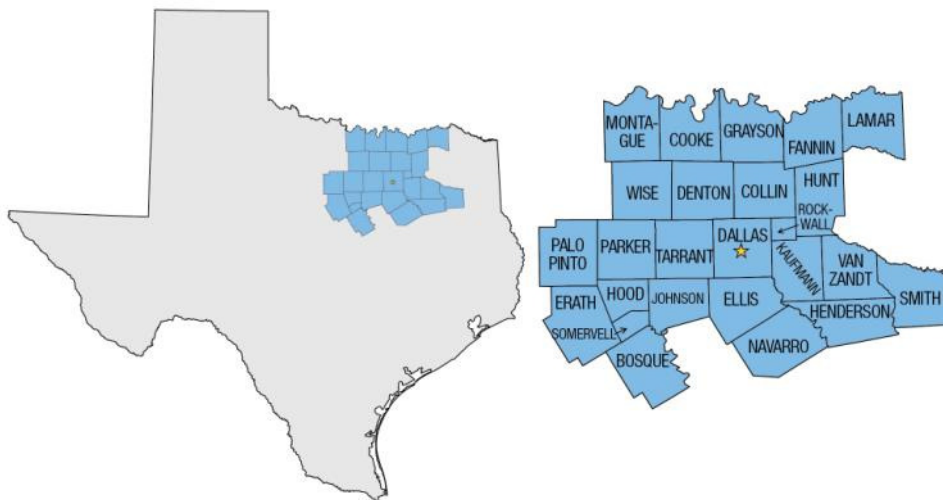
¹¹ International Hip Dysplasia Institute [<http://www.hipdysplasia.org/?gclid=CNetgcqwubgCFYxcMgodywcASQ>].

Other Medical Conditions

TSRHC provides care for children who suffer from neurologic, rheumatologic, and other pediatric developmental disabilities, treated in addition and/or related to other orthopedic conditions. Examples include brain malformations, epilepsy, cerebral palsy and Tuberous Sclerosis Complex (TSC). TSC affects 25,000 – 40,000 individuals in the U.S. with an estimated prevalence of 1/6000 newborns.¹² (See Appendix 1, page 22 for additional TSRHC services provided.)

C. Geographic and Socioeconomic Profile

Although TSRHC is dedicated to providing care to children from across Texas, through a review of patient encounters for calendar years 2011 and 2012, TSRHC determined that more than 80% of its patients live in a 25-county geography located in northeast Texas (See Appendix 4, page 30). This area includes the Texas counties of: Bosque, Collin, Cooke, Dallas, Denton, Ellis, Erath, Fannin, Grayson, Henderson, Hood, Hunt, Johnson, Kaufman, Lamar, Montague, Navarro, Palo Pinto, Parker, Rockwall, Smith, Somervell, Tarrant, Van Zandt, and Wise (hereafter for purposes of this report referred to as “primary service area”). These counties are located in the northeast quadrant of the state and were used as the basis for the socioeconomic profiles and to further define the TSRHC community.



According to the Census Bureau, the estimated population for the primary service area in calendar year 2012 was 7,444,444 people.¹³ The median household income for the

¹² National Institute of Neurological Disorders and Stroke (NINDS) (http://www.ninds.nih.gov/disorders/tuberous_sclerosis/detail_tuberous_sclerosis.htm).

¹³ Texas Association of Counties, County Information Program (CIP) (<http://www.txcip.org/tac/census/CountyProfiles.php> accessed July 2, 2013).

primary service area is \$50,942. This is slightly higher than the median household income for Texas, which is \$50,920, and slightly lower than the median household income for the U.S., which is \$52,762. Approximately 25% of the primary service area population is 18 years or younger. It is interesting to note that more than 75% of patient family households are comprised of four or more people, while the average household size in Texas is 2.79. More than 80% of Texans graduate from high school while 26% graduate from college. These rates mirror those of national data.

III. CHNA METHODOLOGY AND INPUT

The IRS guidance, CHNA resources from the Centers for Disease Control and Prevention, Office of Prevention through Health care, and industry-wide best practices and principles to conducting comprehensive needs assessments were used as a foundation for the methodology used by TSRHC.

A. About Our Consultant

TSRHC engaged the services of the Dallas-Fort Worth Hospital Council Foundation (DFWHCF) to assess the needs of the community and collaborate with TSRHC in producing the final CHNA report. The mission of the DFWHCF is to serve as a catalyst for continual improvement in community health and health care delivery through education, research, communication, collaboration, and coordination. DFWHC is a trusted community resource expanding knowledge and developing new insight for the continuous improvement of health and health care. DFWHCF aligns information collection, analytics, and reporting capabilities to improve clinical effectiveness, care coordination and population health. DFWHCF research staff has more than 15 years experience conducting community health needs assessments and developing comprehensive health service plans.

B. CHNA Planning

A series of collaborative planning sessions were held between DFWHCF health services research staff and the TSRHC CHNA project team comprised of leaders from TSRHC. During these formative planning sessions, the work group determined the most suitable approach to conducting the assessment, the resources necessary, the function of primary and secondary statistics, and the overall collection process and use of qualitative and quantitative data.

- 1. Approach:** A community-based approach using a 12-step process (See Appendix 2, page 29) was employed and allowed TSRHC to use input from patients, their families, and stakeholders with vested interest in the health and well-being of the TSRHC community.

- 2. Primary Data:** Primary data was obtained from patients and key informants through telephone, written and face-to-face surveys.



PATIENTS: The DFWHC contacted 957 patients and their families on behalf of TSRHC during the period of May 14 – July 3, 2013. A randomized sample of patients accessing the five core services areas of the hospital: pediatric orthopedics, neurology, rheumatology, pediatric developmental disabilities and dyslexia, were queried and data was collected for use in this analysis. A significant number of medically underserved, low income and minority patients and patient families were included in the patient survey reflecting the mix of patients seen at TSRHC.

KEY INFORMANTS: Key informant information was collected from 24 identified stakeholders during the period of June 19 – July 12, 2013. Experts in public health, social services, hospital administration, care management, and acute pediatric specialty care were interviewed using a pre-determined list of questions. Key informants represent organizations serving a significant number of medically underserved, low income and minority patients and patient families. A sample of the key informant interview questionnaire may be found in the appendices section of this report. The patient survey and key informant questionnaire as well as a list of participating key informants are included in this report (See Appendices 4, 5 and 6, pages 31 - 35).

- 3. Secondary Data:** Secondary data regarding attributes and factors such as health status, socioeconomic status, standards of care, public health and published guidelines were acquired from a variety of sources, including but not limited to: the Texas Department of State Health Services, Centers for Disease Control and Prevention, Healthy People 2020, Healthy Communities Network, American Community Survey and local public health authorities. Other organizations supporting this CHNA include: Arthritis Foundation, Dallas County Health and Human Services, Dallas-Fort Worth Hospital Council Foundation, Ronald McDonald House of Dallas, and the Tarrant County Department of Health. (See Appendix 7, page 45, for a list of secondary data sources referenced in this report.)

- 4. Community Assessment:** Assessment of the TSRHC community core and ancillary services was accomplished through mixed methodology. Qualitative data was obtained from informants, categorized and interpreted, leading to the identification of trends and anomalies. Quantitative data was collected from patient survey responses, converted to numerical representations, and analyzed with statistical software. Based on an analysis of primary data, presumptions were made and needs identified. State and regional data determined indicators with the most significant impact on health access and quality for the TSRHC community.

IV. SIGNIFICANT COMMUNITY HEALTH NEEDS



A consensus about significant community health needs was reached based on the frequency and importance of survey responses received. DFWHCF and TSRHC leadership identified and prioritized three general needs that reached beyond the specific pediatric orthopedic needs normally identified by our patients. The significant needs identified in this assessment include:

1. Improve Access to Health Care Services
2. Improve Child Health Status
3. Improve Coordination of Care

Where appropriate and practical, TSRHC and the DFWHCF attempted to identify both national and regional pediatric needs with conditions and services that could reasonably be provided by TSRHC, given the hospital's specialized focus. For example, both qualitative and quantitative CHNA research indicates that there is a significant need for pediatric orthopedic services in our geographic markets.

TSRHC will continue to fulfill its primary mission by providing premiere pediatric orthopedic services, conducting pioneering research related to the conditions we treat and providing education in our specialty areas as a leading teaching hospital. Continuing the hospital's mission and policy to treat patients regardless of the family's ability to pay addresses a significant barrier to care identified in community-based research.

A. Need 1: Improved Access to Health Care Services

Statement of Need

A top priority need identified by the CHNA is improved access to health care services. This is further defined as the need for improving access to affordable health care, improving linkage and access to community resources, improving access to preventative health care services and addressing the shortage of certain specialty health care providers.

Supporting Data

More than 55% of key informants reported access to specialty and non-specialty health care as the most critical need of not only TSRHC patients but also the community at-large. Access to appropriate resources is dependent on the affordability, physical accessibility and acceptability of services and not merely adequacy of supply.¹⁴

- Almost a fourth of the TSRHC patient families are single-parent homes. More than a third qualify for public assistance programs; however, only 22% receive government assistance. More than 61% are in transient housing paying rent that meets or exceeds the local fair market values. Eighty-eight percent of adults are employed, yet only 75% have some form of medical insurance. Eighty-eight percent of children reportedly have some form of insurance.
- A fourth of the key informants surveyed said that families often experience financial hardships. This can lead to missed appointments, reduced adherence to prescribed therapies, and hospitalization.
- About half of the key informants identified increasing the number of points of entry as an idea they would like TSRHC to consider. It is presumed that increasing the number of points of entry will allow better access to TSRHC specialty services, especially for those who live in the Dallas-Fort Worth suburbs and beyond.
- More than 55% of survey respondents say that better support systems are needed to help parents and siblings of children with physical and developmental limitations. Most respondents believe that health education could be a beneficial component of a holistic approach to treatment.
- Culture and language are vital factors that have an impact on the delivery of health care. According to the U.S. Department of Health and Human Services, Office of Minority Health,¹⁵ it is important that health care organizations and their staff understand and respond with sensitivity to the needs and preferences that culturally and linguistically diverse patients bring to the health encounter. Providing culturally

¹⁴ Department of Public Health Sciences, King's College London, UK (<http://www.ncbi.nlm.nih.gov/pubmed/12171751>).

¹⁵ U.S. Department of Health and Human Services (OPHS), Office of Minority Health, *National Standards for Culturally and Linguistically Appropriate Services in Health Care*, March, 2001.

and linguistically appropriate services (CLAS) to these patients has the potential to improve access to care, quality of care, and ultimately, health outcomes.

B. Need 2: Improved Child Health Status

Statement of Need

The need for improved health status is the second most essential need identified in the assessment. According to the Child Health USA report for 2012, more than 16 million children under the age of 18 live in households with incomes below 100% of the poverty threshold. Poverty and poor health are inseparably linked, as poverty status directly determines access to nutritional foods, comprehensive medical care, and preventive services. Less than 14% of children nationally participate in 60 or more minutes of physical activity per day, contributing to the obesity epidemic, making it more difficult to treat orthopedic conditions.¹⁶

Supporting Data

- Diabetes and heart disease are two of the most prevalent, preventable chronic conditions in Texas. Sixteen percent of TSRHC patients and families are impacted by diabetes and/or pre-diabetes. More than 8% of the TSRHC patients and families are affected by heart disease. The prevalence of heart disease in Texas residents was 6.6% in 2010¹⁷. Although almost 77% of TSRHC patients and their families report that they are physically active, there exists significant disparity. It is important to note that approximately 3% of the TSRHC patients and families identified in the assessment have co-morbidities of diabetes and heart disease. In addition to diabetes and heart disease, TSRHC has 170 significant co-morbidities that were addressed by the hospital during the twelve month period covered by the CHNA.
- When asked about the needs of TSRHC patients and patient families, juvenile diabetes, obesity, and behavioral/mental health were cited as important needs by both patients and key informants.
- Forty percent of key informants cite diabetes, obesity and poverty as the most critical medical and non-medical issues of pediatric patients (in addition to underlying orthopedic needs), followed by cardiovascular disease, autism, and renal failure. Many of these co-morbidities are not treated at TSRHC, but rather referred to other pediatric providers.

¹⁶ U.S. Department of Health and Human Services, Health Resources and Services Administration, *Child Health USA 2012*, January, 2013.

¹⁷ Texas Behavioral Risk Factor Surveillance System, 2010.

- Many of the key informants expressed concern that conditions such as obesity have the potential to lead to a more acute health status. Obesity and malnutrition can have a significant impact on the capacity of not only providers of service at TSRHC, but also their affiliates and community partners.
- Collaboration and education were the top two methods cited by key informants to comprehensively address patient medical and non-medical needs. Additionally, more patient education regarding healthy lifestyle choices, obesity, and diabetes is believed to be a potential catalyst for improved health outcomes.
- Other patient needs identified by key informants include: mental health services for pediatric patients, resources to help families with limited income, and transportation for those living outside of the Dallas area.

C. Need 3: Better Coordination of Care

Statement of Need

A number of key informants identified better coordination/continuity of care amongst medical providers as an important need. They and other Texas state research initiatives define the ultimate goal of care coordination to ensure relevant information is shared in a meaningful way between the primary practice and other medical community settings such as other non-pediatric orthopedic specialists and community providers of resources integral to the care and quality of life of the community.¹⁸

Supporting Data

- When asked how programs could be improved to meet the needs of TSRHC patients and their families, key informants cited enhancements to care coordination, improved access, and integration of new technology (see use of an Electronic Health Records [EHR] below) as measures that could provide for better continuity of care.
- More than 55% of survey respondents say that better support systems are needed to help parents and siblings of children with physical and developmental limitations. Most respondents believe that health education could be a beneficial component of a holistic approach to treatment.
- Almost 80% of TSRHC patients see a non-TSRHC physician or other professional to help manage their general health while more than 7% do not have access to emergency or after-hour medical care other than that provided at TSRHC. Many indicate that they would like to see more coordination between general

¹⁸ Safety Net Medical Home Initiative, <http://www.safetynetmedicalhome.org/change-concepts/care-coordination>.

practitioners and specialists either through the use of an Electronic Health Record (EHR) or other similar mechanism.

V. RESOURCES TO ADDRESS SIGNIFICANT HEALTH CARE NEEDS

A. Resources to Address Access to Health Care Services

- COST OF CARE AT TSRHC
 - TSRHC Financial Assistance Program – Financial counselors encourage and assist all families to apply for the hospital’s charity care program. Based on household income, the program offers care at no cost or significantly discounted cost to eligible families.

- REFERRAL TO OTHER PROVIDERS

When TSRHC is unable to provide services, TSRHC identifies external resources that are available to the family. Examples of existing health care programs within the community available to address the identified needs include but are not limited to:

 - Children’s Medical Center
 - University of Texas Southwestern Medical Center
 - Cook Children's Medical Center
 - Medical City Children’s Hospital
 - Baylor Institute for Immunology Research
 - Texas Child Neurology
 - North Texas Pediatric Urology
 - Athena Diagnostics

- LODGING
 - Ronald McDonald House & Area Hotels – Many families travel from outside the area to come to TSRHC. Social workers refer families to the Ronald McDonald House (RMH), which provides lodging, meals and transportation at



very little to no cost. When RMH does not have a vacancy, social workers provide a list of other hotels in the vicinity where families may choose to stay.

Families with Medicaid are able to be reimbursed by Medicaid for lodging in most situations. The hospital website has an extensive list of hotels in the area. The list below includes the hotels within a 2-mile radius of the hospital:

Hotel	Phone	Distance (in miles) from TSRHC
Warwick Melrose	(214) 521-5151	0.55
Hyatt Summerfield Suites	(214) 965-9990	0.98
Holiday Inn Market Center	(214) 219-3333	1.06
Doubletree Market Center	(214) 741-7481	1.26
Fairfield Inn	(214) 760-8800	1.35
Courtyard Marriott	(214) 653-1166	1.39

- **TRAVEL/TRANSPORTATION**

- Medicaid Transportation – Families with Medicaid are able to be reimbursed by Medicaid for transportation in most situations. Social workers in the TSRHC Family Services Department are available to help families understand and navigate the processes for Medicaid transportation.
- Southwest Airlines Ticket Vouchers – TSRHC social workers are able to facilitate airline tickets from Southwest Airlines for families living outside the Metroplex that do not have other resources to help with travel to the hospital for appointments. Southwest Airlines donates ticket vouchers to be used by families with no other means of transportation. If such families can get to a Southwest Airlines hub, social workers will coordinate the trip with the family using the vouchers.

B. Resources to Address Child Health Status

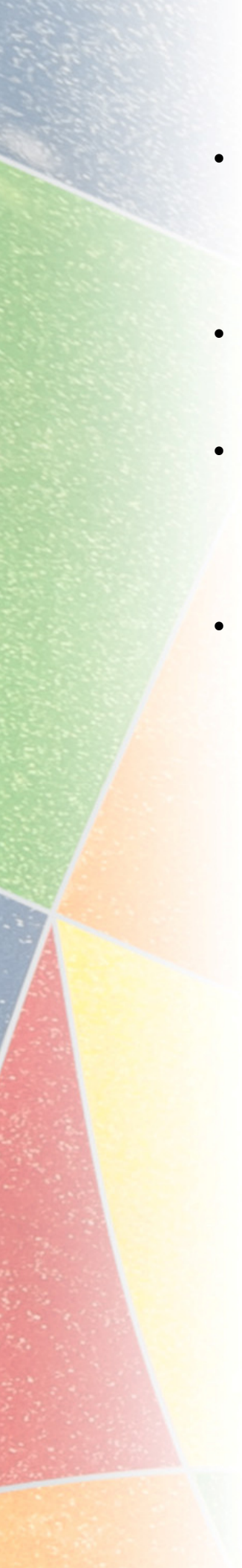
Social workers and Medical Consult Coordinators help families arrange to receive follow-up care with the services listed below as ordered by the medical staff. Patient families choose their vendor(s) from a list of vendors provided by social workers based on location and the patient’s funding source.

- **WEIGHT MANAGEMENT**
 - The Dallas Area Coalition to Prevent Childhood Obesity – TSRHC is an active partner in The Dallas Area Coalition to Prevent Childhood Obesity. TSRHC participates in health fairs and other coalition-led community awareness campaigns, including:
 - Shapedown@ – TSRHC has coordinated this program for patients as well as a multi disciplinary healthy eating class for patients with orthopedic problems.
 - Children's Medical Center (CMC) in the COACH Clinic – TSRHC supports this program, which was established for children who are diabetic or pre-diabetic, and the LEAN Program for weight management. As TSRHC continues to identify children who would benefit from these programs, the appropriate referrals are made to CMC.
 - Medicaid and Children With Special Health Care Needs (CSHCN) programs – These programs also provide support to the TSRHC patients and families and will pay for several visits related to certain weight management issues with a clinical dietitian. As children who would benefit from these services are identified, referrals are made.
- **OUTPATIENT PHYSICAL REHAB** – Physical, occupation and/or speech therapy services are provided in an outpatient setting. Examples include but are not limited to:
 - Our Children’s House at Baylor
 - Cook Children’s Rehab Services
 - Epic Outpatient Rehab
 - Pediatric Rehab – Wellness Care Centers
- **HOME HEALTH SERVICES** – Skilled care is provided in the patient’s home by nurses, physical therapists, occupational therapists, speech therapists and social workers. Examples include but are not limited to:
 - Angels of Care
 - At Home Health Care
 - Epic Health Services
 - Just 4 Kidz Therapy
 - Rehab at Home
 - Therapy 2000 and Small Hands Big Hearts
- **DURABLE MEDICAL EQUIPMENT** – Patients acquire wheelchairs, walkers, canes, crutches, bathroom equipment, hospital beds, pressure relief cushions and other equipment from outside vendors. Social workers, occupational and physical therapists coordinate delivery of this equipment with the vendor and the patient’s family. Examples include but are not limited to:
 - Angels of Care

- Travis Medical Supply
 - J&R Medical
 - Mobility Medical
 - Universal Med Supply
- **MEDICAL SUPPLIES** – Supplies used for feeding, wound care, respiratory care and/or continence are ordered for families using outside vendors. Examples include but are not limited to:
 - All U Med
 - C&R Medical
 - Angels of Care
 - Apria
 - Healthline Medical, Medco
 - Medical Plus Supply
 - Patient Support Services
 - **TESTING AND SPECIALISTS** – Medical Consult Coordinators work with outside providers, facilities and families to schedule tests (ex: genetic testing), procedures (ex: MRI's) and follow-up specialty care (ex: cardiology, urology, nephrology, neurosurgery, genetic counseling, etc.). Examples include but are not limited to:
 - Children's Medical Center
 - Athena Diagnostics
 - Medical City Children's Hospital
 - **MENTAL HEALTH** – Families can receive outpatient mental health services if needed. Social workers and/or psychologists help coordinate follow-up care with these facilities. Examples include but are not limited to:
 - Child and Family Guidance Center
 - Jewish Family and Children's Services
 - Richland Oaks Counseling Center
 - The Family Study Center at the University of Texas Southwestern Medical Center

C. Resources to Address Coordination of Care

In addition to utilizing resources listed in Section V. B. above for care coordination, TSRHC transitions patients to adult providers as they approach the age of 18. A group of TSRHC social workers, nurses, administrators and medical staff work to transition TSRHC patients to ensure that all patients needing additional coordination as they age out of services receive the necessary assistance. Categories of care with which staff helps transition patients to adult care include:

- 
- **LEGAL/GUARDIANSHIP** – For patients who need guardianship after the age of 18, TSRHC social workers help connect families to attorneys that help with the process. The hospital has established a formal relationship with the law firm Vinson & Elkins. They can assist families with pro bono legal assistance with guardianship if the family cannot afford legal services.
 - **PRIMARY CARE AND SPECIALTY CARE** – Social workers help families identify adult care providers. After adult providers accept a patient and permission is received, the patient’s medical records are sent to the receiving physician.
 - **FUNDING** – Funding options change after age 18 or 21, depending on the type of services received. Social workers and financial counselors help families understand options and help them navigate processes to acquire funding as adults. Funding can include government-supported income (SSI/SSDI) and/or medical coverage (Medicaid, Medicare, etc.)
 - **EDUCATION AND/OR VOCATIONAL PROGRAMS** – TSRHC refers patients to programs such as the Department of Assistive and Rehabilitative Services (DARS), which can often help patients with disabilities in finding work and or attending college.

APPENDIX 1: Other TSRHC Medical Services

PROSTHETICS

The Prosthetics Department at TSRHC provides comprehensive prosthetic services and on-site custom fabrication for patients with amputations or limb deficiencies. Since the creation of our Prosthetics Department in 1975, we have fitted more than 5,000 limbs. TSRHC's prosthetists and technicians, all accredited by the American Board for Certification in Prosthetics and Orthotics, complete all phases of prosthetic treatment at the hospital. The phases include: consultation, measuring, casting and molding for prostheses, fitting alignment, fabrication and follow-up visits. The department's full-time prosthetists and technicians work closely with our orthopedic doctors, performing consultations in all of our clinics.

ORTHOTICS

The Orthotics Department at TSRHC provides state-of-the-art, custom-made orthopedic braces, or orthoses, to patients with special orthopedic needs. Our Orthotics Department, which also houses a custom fabrication lab, is located near ambulatory care clinics, allowing our orthotists to collaborate with doctors, therapists and other medical staff on-site during the child's visit. Staff orthotists are dedicated to providing children with the best possible treatment, conducting innovative research and participating in professional orthotics organizations.

NEUROLOGY

Definition: Neurology is a medical specialty dealing with disorders of the nervous system.

Treatment: The Neurology Department at TSRHC provides care for patients who also have neurological disorders related to their orthopedic diagnosis. TSRHC's neurology team provides care limited to related orthopedic conditions that may include care for patients diagnosed with developmental delay, cerebral palsy, brain malformations, epilepsy and other conditions due to brain, spinal cord and peripheral nerve abnormalities such as childhood motor disorders, Tuberous Sclerosis Complex (TSC), holoprosencephaly (HPE) and Hereditary Spastic Paraplegia (HSP).

PEDIATRIC DEVELOPMENTAL DISABILITIES

Definition: Developmental disability is a broad term used to describe a variety of conditions that children experience at birth. Children with developmental disabilities often have physical, social, learning or behavioral challenges. Some of the developmental disabilities seen at the hospital associated with orthopedic conditions include: spina bifida, cerebral palsy (limited to related orthopedic conditions) and certain genetic conditions with orthopedic complications.

Treatment: The Pediatric Developmental Disabilities Department at TSRHC provides care for patients whose orthopedic problems are accompanied by other pediatric medical conditions. An interdisciplinary approach to providing the best possible family-centered care for these children has been adopted and includes physicians whose sub-specialty is neuro-developmental

disabilities; dietitians; physical, occupational, therapeutic and respiratory therapists; and nurse practitioners. In addition to working with the child, the department focuses on teaching family members about the condition and how they can help the child attain optimal physical, mental and social health.

RHEUMATOLOGY

Definition: Rheumatology is devoted to diagnosis and therapy of rheumatic diseases.

Rheumatologists deal mainly with clinical problems involving joints, soft tissues, autoimmune diseases, vasculitis, and heritable connective tissue disorders. Many of these diseases are now known to be disorders of the immune system, and rheumatology is increasingly the study of immunology. Arthritis, which means inflammation of a joint (where two or more bones meet), actually refers to more than 100 different conditions that all fall into the category of rheumatology. Arthritis and other rheumatic conditions are diagnosed by stiffness, swelling, pain and limited movement in joints and other supporting body structures, such as muscles, tendons, ligaments, connective tissues and bones.

Treatment: In 1956, TSRHC established one of the country's first pediatric rheumatology clinics. Today, TSRHC's Rheumatology Clinic is widely recognized as one of the nation's premier clinical treatment and research centers for rheumatic conditions. TSRHC's Pediatric Rheumatology Clinic treats patients with conditions that can cause inflammation in many different parts of the body. Rheumatology conditions most commonly treated at TSRHC include Juvenile arthritis, Dermatomyositis, Vasculitis, and Scleroderma. Other reasons for referral may include prolonged joint swelling or pain, non-traumatic musculoskeletal pain, weakness, rash and fever of unknown origin

Research and Professional Training

TSRHC's Rheumatology Clinic's experience and expertise is enhanced with advanced research to offer accurate diagnostic services and effective pediatric rheumatoid arthritis treatments. TSRHC is actively involved in research regarding treatment of a variety of different rheumatic conditions which has led to innovative treatments for children with juvenile idiopathic arthritis. Our teaching program, one of only 30 in the country, allows fellows to train with our Pediatric Rheumatology team and contribute to the department's research efforts.

CENTER FOR DYSLEXIA AND LEARNING DISORDERS

Definition: Dyslexia is a learning disorder that affects approximately 10 percent of children. Those diagnosed with dyslexia have trouble connecting sounds to letter symbols. This affects the way children with dyslexia learn to read and spell. Fortunately, children with dyslexia can learn to read and be successful despite their learning differences. The center provides

evaluation and diagnosis for children with academic learning disorders, as well as specialized treatment for those with dyslexia. Services include: academic assessment center, dyslexia therapist training, educational outreach and research.

Treatment: The Luke Waites Center for Dyslexia specializes in services for children with learning problems in reading, writing, and math. Evaluations are designed to identify Reading Disorders including Dyslexia, Disorders of Written Expression, and Math Disorders. The scope of practice does not include children whose learning difficulties primarily relate to low cognitive ability, attention emotional or behavioral problems, autism or pervasive developmental disorders, hearing or vision impairment. The Luke Waites Center for Dyslexia's outreach services allow us to expand our mission and help thousands of children through support services for parents and educators. The center offers seminars and workshops to help teachers employ effective teaching strategies. Parents can also obtain guidance in helping their child by attending presentations made to parent support groups and parent education seminars.

Take Time to Read, a partnership between TSRHC and the Masonic Grand Lodge of Texas, is a public awareness program that educates adults about the importance of reading to young children.

TRAINING

Dyslexia Defined: This seminar is designed for educators and parents who want a better understanding of dyslexia. The importance of understanding the definition of dyslexia and how it drives the education processes is the basis of this seminar. TSRHC provides research based information on what dyslexia is and is not. Participants leave with information on the components and delivery of an effective intervention program. The importance of accommodation planning and implementation and hands on practice of comprehension strategy use will be provided.

Take Flight: This is a dyslexia training program provided by TSRHC as a comprehensive intervention for students with Dyslexia. The curriculum contains the five key components of effective reading instruction supported by the National Reading Panel. This curriculum is designed for use by Academic Language Therapists for small group instruction of students with dyslexia (7 years and older). Training consists of an initial three day workshop with two additional one-day follow up sessions scheduled at a later date.

Rite Flight: This workshop addresses two important components identified by the National Reading Panel as needed for effective reading instruction - Reading Rate (Fluency) and Reading Comprehension. Workshop materials include manuals for *Rite Flight: A Classroom Reading Rate Program* and *Rite Flight: A Classroom Comprehension Program*. These materials, developed at

Texas Scottish Rite Hospital for Children, are excellent supplements to a classroom or remedial reading curriculum. They are not intended to provide a comprehensive dyslexia intervention.

School-Based Identification of Dyslexia in Texas: This is a seminar designed for dyslexia designees, dyslexia resource persons, assessment personnel and educators responsible for administering tests and performance measures and/or using results to identify students with dyslexia and recommend placement. This seminar is specifically designed for those with experience in the dyslexia identification process who would like to review, refine and update their knowledge.

Dyslexia Training Program Workshop: This workshop is designed for teachers and paraprofessionals currently facilitating the TSRHC Dyslexia Training Program. It provides the knowledge and tools to implement an effective program using the Dyslexia Training Program. In addition to the Dyslexia Training Program, attendees also learn how to implement the *Rite Flight* supplements. These successful components are a great addition to the Dyslexia Training Program that provides instruction in the specific areas of reading rate and reading comprehension. Participants learn how to incorporate *Rite Flight* into the Dyslexia Training Program to enhance their program.

Developmental-Behavioral Pediatrics - Topics for Primary Care: This course is designed for pediatricians, family practitioners, advanced practice nurses, physician assistants and health care professionals providing direct care to children. The purpose of the seminar is to equip primary care providers to expertly assess, identify and manage developmental and behavioral problems which present between birth and age 18. Lectures, slide presentations and question/answer sessions are presented by guest lecturers and the staff of the Luke Waites Center for Dyslexia and Learning Disorders at Texas Scottish Rite Hospital for Children.

Research: The Luke Waites Center for Dyslexia's research program focuses on the causes and treatment of Dyslexia. Research projects have included studies on:

- The effectiveness of the latest version of the curriculum, *Take Flight: A Comprehensive Intervention for Students With Dyslexia*
- The effects of the curriculum taught in public schools
- The long-term outcome of the center's dyslexia intervention
- The effectiveness of the center's Dyslexia Training Program

The center's research findings have been presented at the World Congress of Dyslexia, the annual conference of the International Dyslexia Association and the Society for the Scientific Study of Reading.

The center's research team has worked with The University of Texas Southwestern Medical Center, The University of Texas at Dallas, and The University of Texas at Arlington. These collaborations have produced publications on mathematical disabilities and the neurobiology of dyslexia treatment response.

CHILD LIFE SERVICES

Child life specialists focus on the social, emotional and developmental needs of infants, children and adolescents in the hospital and promote optimal psychosocial development. Services provided include: preparation and support for medical procedures/surgery, medical play to increase understanding of the hospital and medical equipment and provide an outlet for self-expression, therapeutic play activities, support for caregivers and siblings, education about a new diagnosis, coping techniques for parents, children and adolescents to utilize during medical experiences, child life specialists utilize these techniques to help decrease fear and anxiety and help infants, children and adolescents to cope with hospitalization.

FAMILY SERVICES

The Family Services Department supports patients and their families while they are receiving treatment at TSRHC. Family Services includes these areas: medical social work for resources and referrals, financial assistance programs and family services counseling, language Interpretation and translation services, and coordination of off-site medical services.

FAMILY RESOURCE CENTER

The Christi Carter Urschel Family Resource Center's mission is to provide health information and support resources to patients and families in order to help them make informed health care decisions and improve their quality of life. TSRHC understands that families whose children are diagnosed with special needs have many questions, and the Family Resource Center can help the TSRHC patients and families find answers. A medical librarian and a licensed social worker are available to help patients and families locate information and resources. The collection includes books, magazines, brochures, DVDs, videos and databases covering a variety of medical conditions. TSRHC patient families may check out items from the center for a three week period.

THERAPEUTIC RECREATION

The Therapeutic Recreation Department helps children who have a chronic medical condition or disability develop skills and knowledge needed to be involved in recreation and leisure activities. The department provides an inpatient program to work with children during their hospital stay; ambulatory clinic consults to work with children as part of their clinic appointment and community outreach programs to connect our patients to resources in the community.

Learn to Golf: Learn to Golf was launched in 1998 by the hospital's Therapeutic Recreation Department and was built upon the National Amputee Golf Association's First Swing program. The Learn to Golf program gives hospital patients with physical challenges a hands-on

introduction to the game of golf and provides the tools and instruction needed for patients to participate in and reap the rehabilitative benefits of the game. Each year, hospital patients ages 6 and older from cities across Texas are invited to participate in Learn to Golf clinics. Patients receive specialized training from golf and allied health care professionals, rules book and golf equipment, if needed. In addition, TSRHC may assist patients in finding golf instructors in his or her area who provide junior golf lessons and programs. The Learn to Golf program has received support from generous donors, including World Link, Inc., the North Texas Golf Course Superintendents Association and the National Alliance for Accessible Golf, which is funded through the United States Golf Association (USGA). There is no charge for patients to participate.

PHYSICAL AND OCCUPATIONAL THERAPY

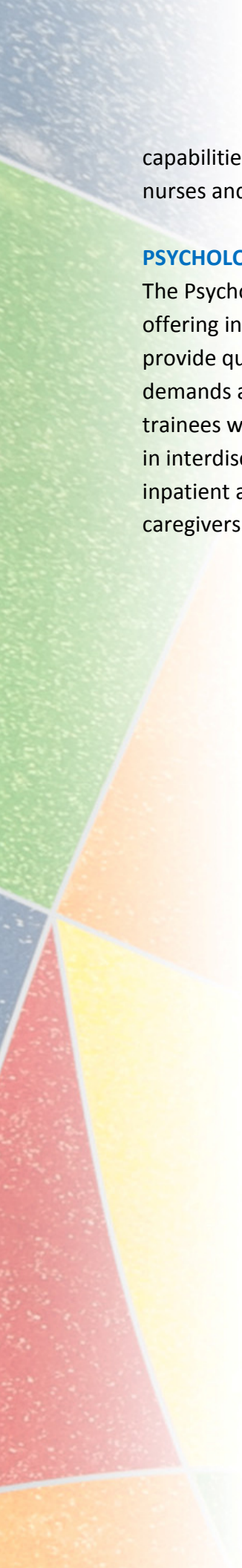
The Physical Therapy Department at TSRHC works with patients to help them develop or maintain maximum movement and ability. Our physical therapists perform various tests to determine the patient's range of motion and muscle strength and make recommendations for walkers, crutches and other durable medical equipment best suited to the child's needs. TSRHC's Occupational Therapy department teaches patients to use specialized equipment and use their bodies in new ways that will help them with activities such as eating and dressing on their own. Children learn skills that will help them gain independence and prepare for living independently as an adult. Occupational therapists also assess patient development; evaluate motor skills, personal and social interaction and language abilities and make recommendations for wheelchairs.

MOVEMENT SCIENCE LABORATORY

The Movement Science Laboratory at TSRHC evaluates patients' walking and movement patterns using 3-D motion capture technology. In the lab, small reflective balls are attached to the child, and special cameras measure the motion of the markers while the child walks across the lab or performs certain motions. The information helps TSRHC medical staff make decisions about the best treatment options for the child.

RADIOLOGY

The hospital's on-site Radiology department assists physicians in providing the highest quality patient care. If a child's orthopedic condition requires imaging, such as CT, MRI or X-ray, the hospital may be able to provide the imaging in the Radiology department, conveniently located in the clinic area. Modern imaging equipment includes a state-of-the-art CT scanner, a high field strength MRI scanner housed in the hospital's Seay/Pickens MRI Center, ultrasound, low-dose digital fluoroscopy and multiple X-ray rooms and OR suites with computed radiography



capabilities. The hospital's Picture Archive and Communication System (PACS) allows physicians, nurses and other medical staff to access a child's medical images throughout the campus.

PSYCHOLOGY

The Psychology Department helps patients and their families deal with stress constructively, offering individual and family counseling. The purpose of the Psychology Department is to provide quality clinical care and promote healthy child development, despite the stress and demands associated with a health-related condition. Licensed psychologists and psychology trainees with expertise in pediatric psychology and behavioral health coordinate and participate in interdisciplinary health care, related teams, hospital committees and research. Direct clinical inpatient and outpatient services are provided to TSRHC patients, along with their families and caregivers.

APPENDIX 2: Adopted 12-Step Process¹⁹

Step 1	Confirm the Issues and Audience. Establish the purpose of the needs assessment. Determine if it is a legal requirement, a company requirement, etc.
Step 2	Establish the Planning Team. Establish the planning team while determining available resources.
Step 3	Establish Goals and Objectives. Establish goals and objectives in three phases: (1) identify the optimum and actual levels of knowledge, (2) identify the causes for lack of knowledge, and (3) devise solutions.
Step 4	Characterize Your Audience. Determine audience characteristics: sample size, skill knowledge, education level, organization niche, cultural biases, and attitudes.
Step 5	Conduct Information and Literature Search. Review published guidelines and literature. Surveys are often used to clarify perceptions or answer questions that may surface during a review of literature.
Step 6	Select Your Data Collection Methods. Determine how data will be collected (e.g.: personal interviews, surveys, tests).
Step 7	Determine Your Sampling Scheme. Determine the sample size.
Step 8	Design and Pilot the Collection Instruments. Validate the instruments.
Step 9	Gather and Report Data. Develop strategies for increasing response rate while ensuring anonymity of respondents.
Step 10	Analyze Data. Develop a system that keeps findings and interpretation of findings separate (collection and final report).
Step 11	Manage Data. Determine how data will be organized and archived.
Step 12	Synthesize Data and Create Report. Address goals and objectives in synthesis. Report must include an evaluation of the design and implementation of the survey.

¹⁹ NOAA Needs Assessment Training (http://www.csc.noaa.gov/needs/12_steps.html).

APPENDIX 3: Primary Service Area Population and Demographics²⁰

County	Population	AA%	W%	H/L%	Asian%	AI/AN%	2+%	≤17yr%
Bosque	18,125	1.8	95.7	16.1	0.4	0.7	1.3	22.2
Collin	834,642	9.0	76.1	14.9	11.7	0.7	2.3	27.8
Cooke	38,688	2.9	93.3	16.1	0.9	1.3	1.5	25.1
Dallas	2,453,843	22.8	69.0	38.7	5.4	1.1	1.6	27.3
Denton	707,304	8.8	80.9	18.5	7.0	0.9	2.3	26.9
Ellis	153,969	9.2	87.8	24.0	0.6	0.8	1.4	28.0
Erath	39,321	1.4	95.2	19.3	0.8	1.6	1.2	21.5
Fannin	33,831	6.9	89.4	10.0	0.4	1.2	2.0	21.6
Grayson	121,935	6.0	88.9	11.5	1.0	1.7	2.3	23.8
Henderson	79,094	6.5	90.6	11.2	0.5	0.7	1.6	22.5
Hood	52,044	0.6	96.6	10.6	0.7	0.9	1.1	20.5
Hunt	87,079	8.5	87.1	14.0	1.1	1.2	1.9	24.7
Johnson	153,441	2.9	93.5	18.6	0.8	0.9	1.6	26.7
Kaufmann	106,753	10.5	85.9	17.7	1.0	0.9	1.6	28.3
Lamar	49,811	13.6	81.5	6.7	0.7	1.7	2.5	23.8
Montague	19,565	0.4	96.7	9.9	0.4	1.1	1.2	22.8
Navarro	47,979	14.1	82.1	24.2	0.7	1.0	1.4	27.2
Palo Pinto	27,856	2.3	94.9	18.3	0.6	0.9	1.3	24.4
Parker	119,712	1.8	95.1	10.9	0.6	0.9	1.5	24.4
Rockwall	83,021	6.0	89.0	16.2	2.6	0.7	1.6	28.5
Smith	214,821	18.2	78.1	17.6	1.3	0.8	1.5	25.4
Somervell	8,598	1.0	95.0	18.9	0.8	1.4	1.8	25.0
Tarrant	1,880,153	15.4	76.5	27.1	4.9	0.9	2.1	27.5
Van Zandt	52,427	2.8	94.3	9.6	0.4	1.0	1.4	23.7
Wise	60,432	1.2	95.9	17.5	0.5	1.0	1.3	25.7
Total/Avg	7,444,444	7.0	88.4	16.7	1.8	1.0	1.6	25.0

²⁰ Texas Association of Counties, County Information Program (CIP)
<http://www.txcip.org/tac/census/CountyProfiles.php>.

APPENDIX 4: Patient Survey²¹

Section 1: Demographics

1. How many people live in the home?
2. How many in the home are 18 years or younger?
3. What is your race?
4. What is your zip code?

Section 2: TSRHC Ancillary Service-Specific Questions

1. Have you ever received any of the following services from TSRHC?

Care management (case management, nutrition counseling, therapy, support groups)

Financial assistance (help with paying for medical expenses)

A place to stay overnight while your child received medical services (if living more than 50 miles from TSRHC)

Translation/linguistic services (if English is the second language of the home)

Transportation to and from appointments

Durable medical equipment

Pharmacy/medication assistance

Health education

Scholarship or opportunity to volunteer (give back) to TSRHC

2. Are there any services TSRHC did not provide or offer help in finding that could have made things better for you or your family while your child was in their care?

(Open answer question)

Section 3: Social Environment

1. Are you a single parent?

²¹ Patient Survey developed by Crystee Cooper-Walton, Director of Health Services Research, DFWHC Foundation, April 2013.

2. What is the preferred language spoken in the home?

Section 4: Transportation

1. Do you have access to or use public transportation?

2. Do you have access to emergency health services (such as an emergency room or doctor office with extended hours)?

3. Does your child see a doctor that is not located at TSRHC? If so what kind of doctor and where (hospital and city)?

Section 5: Health

1. Is anyone in the home diagnosed with diabetes or pre-diabetes?

2. Is anyone in the home diagnosed with heart disease?

3. Approximately how many hours per week do you or members of your household exercise?

Section 6: Economy

1. Do any of the adults in the home have health insurance?

2. Do any of the children in the home have health insurance?

3. Is at least one person in the home employed?

4. What is your household income per year from all sources?

5. Do you rent or own your home?

6. How much is your rent or mortgage?

7. Do you receive any government assistance such as SNAP (food stamps), WIC, or monthly financial assistance (welfare)?

APPENDIX 5: Key Informant Interview Questions²²

General

How long have you partnered/worked/had a relationship with TSRHC?

Why do you/would you refer your patients to TSRHC?

What kind of feedback do you get from your patients regarding their experience with TSRHC?

Are there any other pediatric orthopedic hospitals or similar specialty clinics you refer patients to other than TSRHC? If so who, where, and why?

TSRHC Services

What types of barriers have you experienced when referring patients to/serving patients within TSRHC?

What are some of the ____ (program/service line/hospital) ____ strengths?

How could the ____ (program/service line/hospital) ____ be improved to better meet the needs of patients and patient families?

Can you give me an example of at least one idea or program you'd like to see discussed or implemented by either TSRHC or someone else within the community within the next 1-3 years that could have a direct impact on pediatric patients?

Community

What are some of the most critical medical/health and non-medical/health needs of your patients/the public?

What impact (if any) do non-medical needs of patients have on their overall health?

What does your organization do to help close the gap in meeting non-medical needs?

In your opinion, what is the best way for the community as a whole to address the medical/health and non-medical/health needs of patients and their families?

What role do you think health care providers/hospitals should play in community benefit?

Are you involved in any community coalitions/collaboratives/partnerships focused on community benefit? If so, what are their names and purpose?

²² Informant Questionnaire developed by Crystee Cooper-Walton, Director of Health Services Research, DFWHC Foundation, May, 2013.

*****TSRHC Internal Key Informants Only*****

How well does TSRHC integrate its commitment to community service into its governance structure?

How should TSRHC approach community benefit?

What has TSRHC done in the past 1-3 years to help build organizational and community capacity to serve disabled children and their families?

APPENDIX 6: Participating Key Informants

Pediatric Orthopedics

- Dan Sucato, M.D., TSRHC
- Adam Starr, M.D., UT Southwestern Medical Center
- Marybeth Ezaki, M.D., TSRHC
- J.A. “Tony” Herring, M.D., TSRHC
- B. Stevens Richards, M.D., TSRHC

Dyslexia

- Jeffrey Black, M.D., TSRHC, Luke Waites Center for Dyslexia
- Gladys Kolenovsky, TSRHC Luke Waites Center for Dyslexia
- Daniel Ramirez, M.D., Kid's Doc Pediatric Associates

Neurology

- Mauricio Delgado, M.D., TSRHC
- Anthony Riela, M.D., Texas Child Neurology
- Mark Goldberg, M.D., University of Texas Southwestern Medical Center

Rheumatology

- Marilyn Punaro, M.D., TSRHC
- Pam Gill, Arthritis Foundation
- Serena Heins, Arthritis Foundation

Pediatric Developmental Disabilities

- Richard Adams, M.D., TSRHC
- Veronica Meneses, M.D., TSRHC
- Joyce Mauk, M.D., Child Study Center

Other

- David Roberts, M.D., TSRHC
- David Ewalt, M.D., North Texas Pediatric Urology
- Peter Schochet, M.D., Pulmonologist
- Jill Cumnock, ACSW, LCSW, LMFT, Ronald McDonald House of Dallas
- Zachary Thompson, MA, Dallas County Health and Human Services
- Lou Brewer, RN, MPH, Tarrant County Health Department
- Kristin Jenkins, JD, MBA, FACHE, Dallas-Fort Worth Hospital Council Foundation

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