



The Children with Special Health Care Needs Project

Needs Assessment Report

The Children with Special Health Care Needs Project: Needs Assessment Report

Needs Assessment Team

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Sponsor/Funder

This Needs Assessment project was conducted as part of a three-year contract with the Texas Department of State Health Services to develop a best-practices case management practice model for children with special health care needs in Texas. Points of view in this report are those of the authors and participants and do not necessarily represent the official positions or policies of the Texas Department of State Health Services.

Acknowledgements

The needs assessment team would like thank staff and parents of children with special health care needs who took the time to share their personal experiences with us.

Recommended Citation

Nulu, S., Gerlach, B., Holmes, S., Hough, C., Marcos, A. & McKerlie, K. (2021). *The Children with Special Health Care Needs Project: Needs Assessment Report*. Austin, TX: The University of Texas at Austin.

Table of Contents

- EXECUTIVE SUMMARY 1
- BACKGROUND..... 2
- LITERATURE REVIEW** 2
- ABOUT THIS LITERATURE REVIEW 3
- BACKGROUND OF CSHCN IN TEXAS 3
- NATIONAL STANDARDS OF CSHCN 5
- IDENTIFICATION, SCREENING, ASSESSMENT, AND REFERRAL 6
- ACCESS TO CARE..... 11
- CARE COORDINATION & MEDICAL HOME..... 15
- COMMUNITY-BASED SERVICES & SUPPORTS 17
- TRANSITION TO ADULTHOOD 18
- ABOUT CASE MANAGEMENT 22
- TYPES OF CASE MANAGEMENT PRACTICE MODELS..... 25
- BEST PRACTICE IN CASE MANAGEMENT MODEL DEVELOPMENT 26
- COMPONENTS OF BEST PRACTICE CASE MANAGEMENT MODELS 28
- CONCLUSION 30
- NEEDS ASSESSMENT OF CSHCN CASE MANAGEMENT IN TEXAS 31
- NEEDS ASSESSMENT** 31
- NEEDS ASSESSMENT OF CSHCN CASE MANAGEMENT IN TEXAS 32
- RESEARCH QUESTIONS..... 32
- DESIGN & METHODOLOGY 32
- NEEDS ASSESSMENT OUTCOMES: STATE COLLECTED DATA 36
- NEEDS ASSESSMENT FINDINGS 42
- LIMITATIONS 68
- RECOMMENDATIONS..... 69
- CONCLUSION 71
- LOOKING FORWARD..... 72
- REFERENCES..... 73
- APPENDIX A: CSHCN CONTRACTORS 77
- APPENDIX B: PRE-INTERVIEW FORM..... 79
- APPENDIX C: INTERVIEW GUIDES 84
- APPENDIX D: ADDITIONAL DATA 89
- APPENDIX E: SUMMARY OF COVID-19 IMPACTS 99

Executive Summary

This Needs Assessment report is part of a three-year contract between the Texas Institute for Child & Family Wellbeing (TXICFW) and the Texas Department of State Health Services for TXICFW to develop a best practices case management model specific to serving families with children with special health care needs (CSHCN). To better understand best practices case management model for CSHCN and their families in Texas, TXICFW conducted: 1) a literature review of existing research and best practices on providing care for CSHCN and their families, and 2) a Needs Assessment of how case management services are currently being provided to CSHCN and their families in Texas.

1. What are the processes and protocols for providing case management to CSHCN?
2. What are the strengths and challenges in how regions are providing case management to CSHCN?
3. What are the issues that need to be considered in improving each of these 5 domains of CSHCN care (National Standards of CSHCN)?
 - i. Identification, Screening, Assessment, and Referral
 - ii. Access to Care
 - iii. Medical Home and Care Coordination
 - iv. Community-based Services and Supports
 - v. Transition to Adulthood

Literature Review

The literature review includes a review of best practice research on providing care for CSHCN and their families and best practices research on case management model development. A foundational resource that was identified during the review of literature on CSHCN was [the National Standards for Children and Youth with Special Health Care Needs](#), referred to as the National Standards of CSHCN in this report.

Needs Assessment of CSHCN Case Management in Texas

The Needs Assessment was a mixed-methods research design that collected data from qualitative interviews/focus groups and a quantitative online survey completed by caregivers of CSHCN, CSHCN staff, and stakeholders. This Needs Assessment was guided by the following research questions with the goal of understanding how case management services are provided to CSHCN families in Texas by DSHS regional staff and CSHCN contractors.

Recommendations

Based on the literature review and Needs Assessment findings, TXICFW presents the following recommendations for the development of the CSHCN case management practice model.

1. Improve Data Collection
2. Expand eligibility of case management programming to encompass mental/behavioral health
3. Continue DSHS Intake Process and Update Family Needs Assessment
4. Incorporate the CSHCN's siblings when developing service plans and goals for CSHCN and their families
5. Strengthen collaboration and care coordination with providers
6. Establish consistency in transition age planning for CSHCN

Background

Approximately 19% of children among all household in the United States have special health care needs (CSHCN).¹ Children and youth with special health care needs are defined as “children from birth to age 21 who have or are at an increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”² Families caring for CSHCN find themselves navigating various complex systems such as healthcare, insurance, behavioral health services, and school systems that are rarely coordinated. Often, navigating these systems is a convoluted and burdensome process to obtain even the minimum care needed for their child.

Case management is a particularly important service for CSHCN and their families in that it can provide much needed support and understanding of the services available, help families navigate various systems, and advocate for families interacting directly with these systems. The Children with Special Health Care Needs Project is focused on case management services to the CSHCN population in Texas, which is implemented and overseen by the Texas Department of State Health Services (DSHS).

About the CSHCN Project

The Texas Institute for Child & Family Wellbeing (TXICFW) has been contracted by the Texas Department of State Health Services (DSHS) to complete the following:

1. Conduct a Needs Assessment of CSHCN case management programming implemented by DSHS in Texas;

2. Develop a case management practice model;
3. Develop and implement a quality assurance and evaluation process for that model; and
4. Provide training and ongoing technical assistance to DSHS.

For this project, TXICFW is collaborating with the CSHCN Systems Development Group and the Regional and Local Health Operations divisions at DSHS to identify best practices and support consistent implementation of case management services provided for CSHCN and their families in Texas.

This report covers the activities and outcomes of the Needs Assessment portion of this project including:

1. Literature Review of CSHCN and Case Management Practice Models; and
2. Needs Assessment of DSHS case management services for CSHCN in Texas.

Project Goal

The goal of this project is to ensure all case management services are high-quality, family-centered, and culturally responsive.

Project Plan

This project will be conducted in three phases from 2020 - 2023: Needs Assessment, Practice Model Development, and Training and Guidance.

FIGURE 1. CSHCN PROJECT TIMELINE



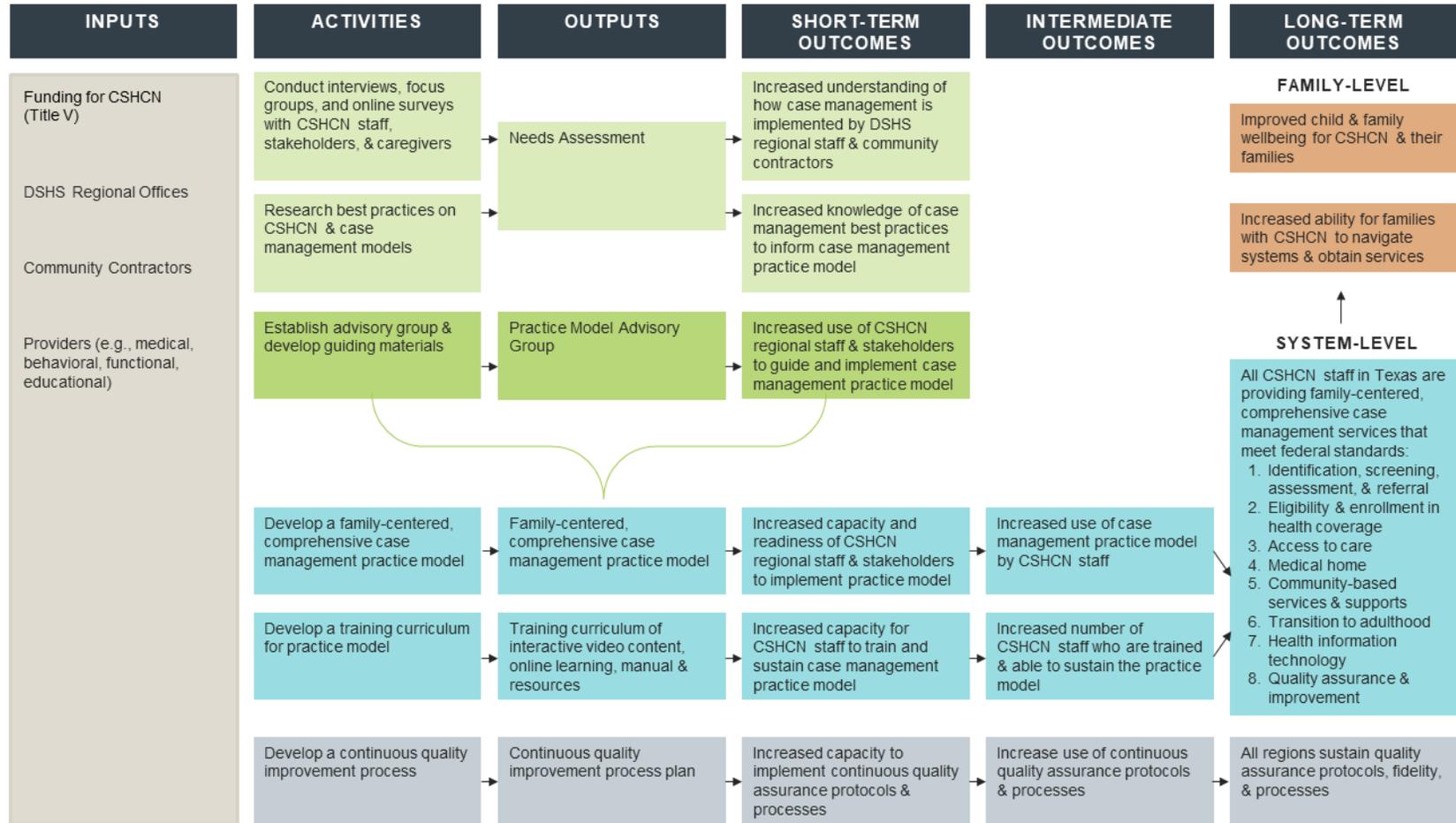
Logic Model

Figure 2 below is the logic model of the CSHCN Project that provides an overview of the inputs, activities, outputs, and outcomes of this project. Although the examination of short, intermediate, and long-term is beyond the scope of this project, it is included in this logic model to provide context of the theoretical impacts based on best-practices research.

FIGURE 2. CSHCN PROJECT LOGIC MODEL

TXICFW Children with Special Health Care Needs Project Logic Model

Project Goal: To ensure all case management services for CSHCN and their families in Texas are high-quality, family-centered, and culturally sensitive.





Literature Review

About this Literature Review

The purpose of this literature review is to understand existing research on CSHCN in order to inform the development of tools to conduct the Needs Assessment and develop the practice model for the CSHCN case management program in Texas. The goals of this literature review are to:

1. Understand the scope of the Children with Special Health Care Needs (CSHCN) programs in Texas;
2. Present evidence-based and/or peer-reviewed research related to providing services for the CSHCN population; and
3. Share best practices in case management practice model development and examine current evidence-based case management practices used by professionals who serve CSHCN.

The literature review will cover four topics, outlined below:

1. CSHCN Background: An overview of the CSHCN program and CSHCN case management implementation in Texas
2. National Standards of CSHCN: Overview of the National Standards for Children and Youth with Special Health Care Needs
3. CSHCN Data: Best practices research on CSHCN and data on the CSHCN population Nationally and in Texas
4. Case Management Practice Models: Best-practices research of case management practice models



Background of CSHCN in Texas

The Texas Department of State Health Services (DSHS) and the Texas Health and Human Services Commission (HHSC) implement programming and services for the children with special health care needs (CSHCN) population in Texas. While the two state agencies serve the same population, the types of services they provide to CSHCN are different. HHSC implements the CSHCN Services Program that is a healthcare benefit program, which is the payor of last resort for healthcare services for CSHCN not covered by Medicaid, CHIP, private insurance, or another party.³ DSHS implements case management services to children and families through two internal divisions:

1. the Maternal and Child Health Unit that contracts with case managers at community organizations, referred to in this report as CSHCN contractors, and
2. the Regional and Local Health Operations department that manages regional case managers at 8 regional state offices.

Together, the CSHCN contractors and case managers at regional DSHS offices provide case management services and ancillary support for the CSHCN population in Texas. Case managers connect families to a variety of services, including assistance with care coordination, referral to respite care, transportation services, insurance services, and medical, behavioral, and occupational therapies

for children and their caregivers. The DSHS CSHCN case management services are provided to families who have a CSHCN, including families who are receiving benefits from the CSHCN Services Program as well as families who are not receiving any benefits.

Currently, every region in Texas implements case management services differently for families with CSHCN. While the effort of CSHCN case managers is to individualize services for each family, there is a need to establish consistency in policies and implementation of case management services across the state to ensure high-level care.

Eligibility Requirements

While the HHSC and DSHS CSHCN programs both serve the same population, eligibility requirements for program participation are different, as described in the table below. Looking at these eligibility requirements, the DSHS programming is able to serve a wider range of needs among children since it has broader eligibility requirements regarding the type of health diagnosis present among children. As stated previously, DSHS provides the case management component for the CSHCN population in Texas, while the HHSC CSHCN Services Program only provides healthcare coverage.

TABLE 1. ELIGIBILITY REQUIREMENTS FOR CSHCN SERVICES

ELIGIBILITY REQUIREMENTS	HHSC CSHCN SERVICES PROGRAM	DSHS CSHCN SYSTEMS DEVELOPMENT GROUP	DSHS REGIONAL AND LOCAL HEALTH OPERATIONS
TEXAS RESIDENCY	✓	✓	✓
AGE	20 or younger, any age if person has cystic fibrosis	20 or younger, any age if person has cystic fibrosis	21 or younger, any age if person has cystic fibrosis
CONDITION TYPE	Chronic physical condition only that is expected to last at least one year	Condition or risk of condition that is chronic physical, developmental, behavioral, or emotional	Condition is biological, physical, or cognitive that is expected to last at least one year
LIMITATIONS	Will limit one or more major life activities	N/A	Has limited function, activities, or social roles in comparison with healthy age peers in general areas of physical, cognitive, emotional, and social growth and development

Data Source: CSHCN Services Program⁴, CHSCN Systems Development Group⁵, and DSHS Regional and Local Health Operations CSHCN case management program⁶.

Note: HHSC eligibility requirements state “condition” but the condition must be an ICD diagnosis code.

Funding for CSHCN Services

Every state's CSHCN program receives some of their funding through the Title V Maternal and Child Health Block Grant (Title V of the Social Security Act).⁷ The Title V Maternal and Child Health Block Grant is a federal grant allocated to states and operated through state-federal partnerships.⁷ While there are other programs that serve children with special health care needs, Title V is the only one with specific responsibility for this population.⁷ At least 30% of the Title V funding provided to each state must be designated for services for CSHCN.⁷ Allocation of the Maternal and Child Health block grant for each state is determined by an algorithm that takes into consideration the proportion of low-income children in a state with the total number of low-income children within all states.⁷ For FY2018, the federal portion of the Maternal Child Health Block Grant for Texas was \$34.5 million.⁸ For FY2018, the projected budget showed that \$13,269,457 was earmarked directly for children with special health care needs in Texas, which is approximately 39% of the federal allocation.⁸

Since each state's organizational and implementation systems vary greatly, it is difficult draw comparisons on the amounts of funding and outcomes. However, it is important to note that in addition to Title V federal funding, states may have other sources of funding to implement programming and services for CSHCN.

National Standards of CSHCN

The National Standards for CSHCN were developed by the National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs Project, funded by the Lucille Packard Foundation for Children's Health in 2014.⁹ These standards were developed based on decades of best-practices research, key informant interviews, case studies,

and a national work group whose participants included national and state leaders representing Title V CSHCN programs, state Medicaid and CHIP agencies, healthcare providers, insurers, health service researchers, and CSHCN families, among others. These National Standards were then vetted by a diverse collaborative group made up of state and national leaders with expertise in CSHCN, health systems, and quality measurement.⁹

The National Standards were developed with the purpose to be utilized within health care systems to improve both the quality and outcomes for CSHCN.⁹ These National Standards are now ubiquitously used by national, state, and local stakeholder groups and organizations including many state Title V CSHCN programs, state Medicaid and CHIP agencies, pediatric provider organizations, among many others. The next section describes the four foundational standards and the eight core domains of the established National Standards of CSHCN.

While these National Standards for CSHCN are primarily focused on the CSHCN in a predominantly medical healthcare setting, as opposed to a comprehensive focus around the health and wellbeing of the whole family, they do provide an important foundation of best practices research and guiding principles when developing a best practice case management model specific for CSHCN families.

Foundational Standards & Core Domains for Systems of Care for CSHCN

Figure 3 below describes the federally defined Foundational Standards for Systems of Care and the Core Domains for CSHCN.⁹

Figure 3 below describes the federally defined Foundational Standards for Systems of Care and the Core Domains for CSHCN.⁹

FIGURE 3. FOUNDATIONAL STANDARDS & CORE DOMAINS FOR CSHCN



1. Children and families of CSHCN are active, core partners in decision making in all levels of care.
2. All services and supports for CSHCN are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CSHCN and their families.
3. Insurance coverage for CSHCN is accessible, comprehensive, and continuous.
4. All care provided to CSHCN and their families is evidence-based when possible, and evidence-informed on promising practices where evidence-based approaches do not exist.

- a. *Pediatric Preventative and Primary Care*
- b. *Medical Home Management*
- c. *Care Coordination*
- d. *Pediatric Specialty Care*

5. *Community-based Services and Supports*

- a. *Respite Care*
- b. *Palliative and Hospice Care*
- c. *Home-based Services*

6. *Transition into Adulthood*

7. Health Information Technology
8. Quality Assurance and Improvement

The scope of the CSHCN project will be primarily focused on the **five of the eight domains in blue** above: Identification, Screening, Assessment, and Referral; Access to Care; Medical Home; Community-based Services and Supports; and Transition into Adulthood. The next five sections of this literature review will discuss data outcomes, research based on these five domains.

Core Domains of CSHCN

1. *Identification, Screening, Assessment, and Referral*
2. Eligibility and Enrollment in Health Coverage
3. *Access to Care*
4. *Medical Home*

Identification, Screening, Assessment, and Referral

The systems standard that guides the *Identification, Screening, Assessment, and Referral* domain is that “Children are screened early and continuously for special health care needs.”⁹ Identification refers to having a definition of CSHCN explaining who

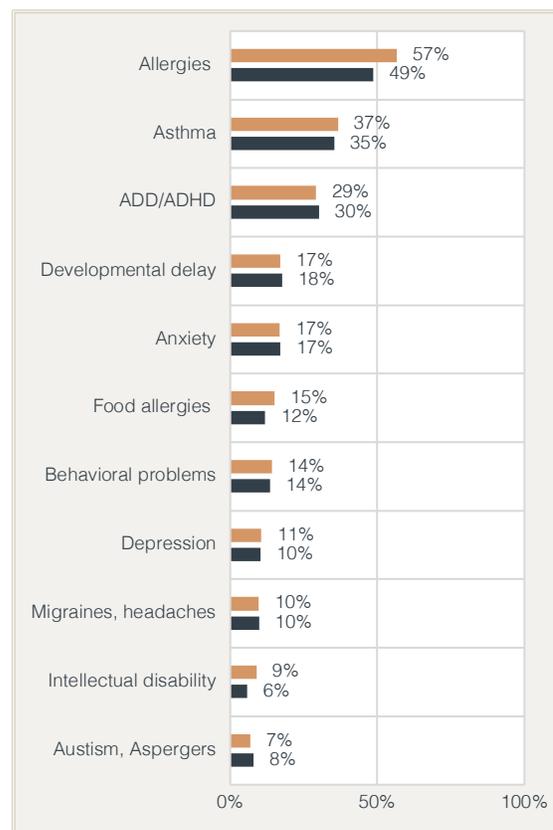
qualifies for services as well as identifying insurance coverage options available for CSHCN. Screening refers to ensuring early and developmentally appropriate screening for CSHCN, particularly among newborns and infants. Assessment may encompass a variety of different assessments depending on the specific health care needs, however all assessments should be conducted timely and documented appropriately. Based on the assessments, referrals are made to the appropriate providers, such as specialists or therapists.

The data presented below is from the National Survey for Children with Special Health Care Needs (NS-CSHCN), which provides insight about the types of conditions experienced by CSHCN and demographics of CSHCN and their families.

CSHCN Conditions

The 2009/2010 NS-CSHCN asked respondents whether their child experiences specific conditions from a list of 21 health conditions comprised of physical, mental, behavioral, and developmental conditions. Figure 4 below shows the type of health conditions prevalent among CSHCN, comparing respondents from Texas and among all survey respondents (national).

FIGURE 4. CONDITIONS AMONG CSHCN, TEXAS & NATIONALLY

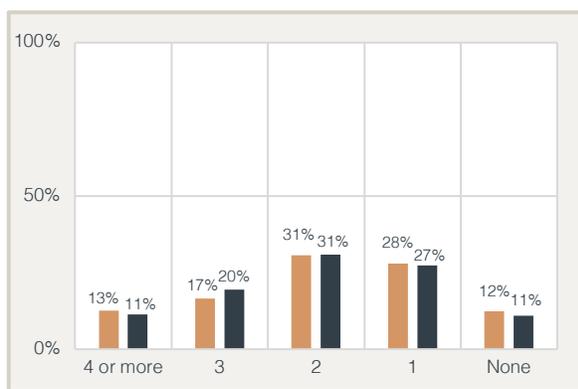


Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,239

ADD refers to Attention Deficit Disorder and ADHD refers to Attention-deficit/Hyperactive Disorder. Developmental delay includes learning disorders, and Behavioral problems includes conduct disorders. The following conditions were experienced by 5% or fewer nationally and for Texas, respectively: Epilepsy/seizure disorder (3%, 4%), heart problems (3%, 3%), head injury/concussion/traumatic brain injury (1%, 2%), arthritis/joint problems (3%, 2%), anemia/sickle cell (2%, 1%), Down Syndrome (1%, 1%), muscular dystrophy (<1%, <1%), and cystic fibrosis (<1%, <1%). To reiterate, these are only the conditions about which the survey specifically asked participants. There may be other conditions experienced by children that were not captured in these categories.

The top conditions experienced by CSHCN are physical conditions (allergies and asthma), followed by developmental conditions (ADD/ADHD and developmental delays). While there is often a primary condition, many CSHCN experience multiple conditions that impact their health and wellbeing. Figure 5 below shows the prevalence of the number of conditions experienced by CSHCN from the NS-CSHCN survey.

FIGURE 5. NUMBER OF CONDITIONS EXPERIENCED BY CSHCN, **TEXAS** & **NATIONALLY**



Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,239

The conditions reported are from the list of 21 conditions asked in the survey. Approximately one-third of survey respondents had children currently experiencing two conditions considered as special health care needs. No conditions reported represents the number of families surveyed whose children did not have a condition from the 21 conditions asked about on the survey.

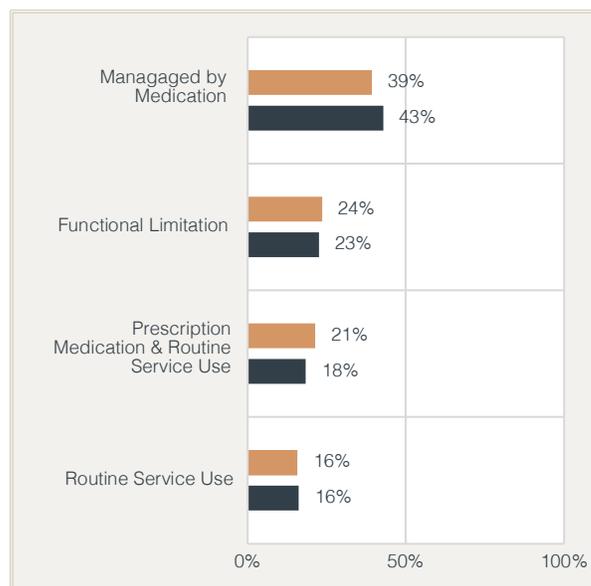
In order to understand the broad impacts of CSHCN conditions, the NS-CSHCN identified three general condition impact groups:

1. The CSHCN condition is **managed by prescription medication**,
2. The CSHCN condition is a **functional limitation**, and

3. The CSHCN condition requires **routine service use** of medical care, mental health, or education services.

Figure 6 below compares Texas and national percentages of survey respondents who self-described the impact of their child's condition.

FIGURE 6. IMPACT OF CSHCN CONDITION, **TEXAS** & **NATIONALLY**



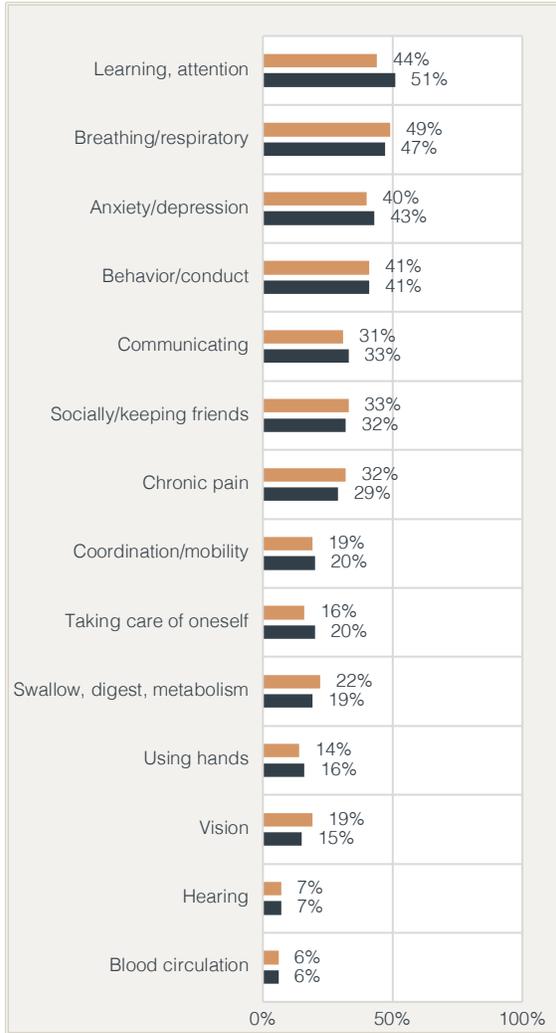
Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,242

This data shows that a greater percentage of CSHCN are able to manage their condition with appropriate prescription medication. The next more widely impacted group includes children experiencing a functional limitation. The latter two impacted groups include routine service use of medical care, mental health, or education services in conjunction with prescription medication, followed by routine service use alone.

Figure 7 describes the functional limitations. While the definition of "functional difficulty" is broad and not clearly defined in the survey, it does provide some context of the type of

functional challenges experienced by CSHCN.

FIGURE 7. FUNCTIONAL DIFFICULTIES AMONG CSHCN, TEXAS & NATIONALLY



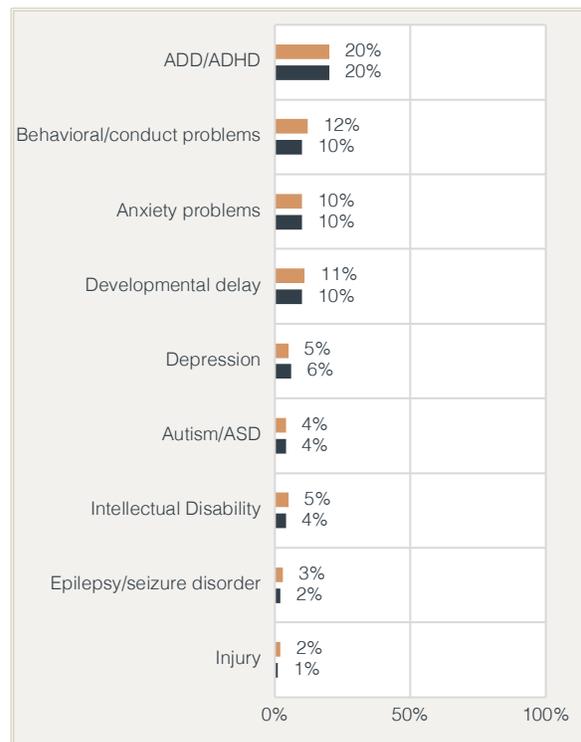
Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,242

The top functional difficulties were: 1) Learning, understanding, attention; 2) Breathing/respiratory functions; 3) Anxiety/depression; 4) Behavior/conduct; and 5) Communicating.

Figure 8 presents the conditions rated as moderate/high severity by survey respondents. The NS-CSHCN question did not define severity, therefore the

designation of severity level is subjective. Behavioral health, mental health, emotional health, and developmental conditions were considered most severe, compared to physical conditions. However, severity of a condition does not always correspond with functional ability. For example, a less severe physical disability may require more health care service use or medication management compared to a severe developmental disability, or vice versa.

FIGURE 8. MODERATE/HIGH SEVERITY OF CSHCN CONDITIONS, TEXAS & NATIONALLY



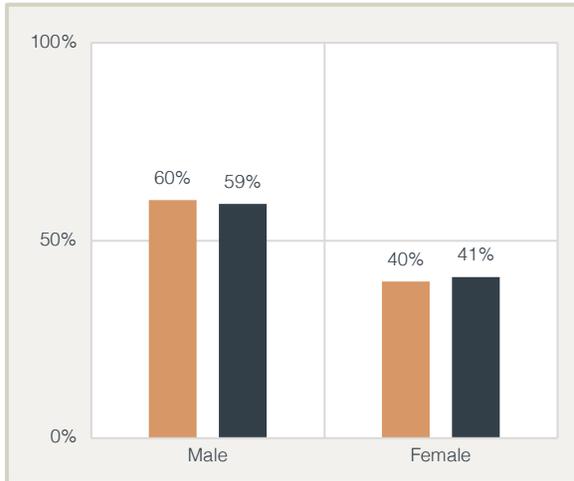
Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,242

Demographics of CSHCN

This next section will present demographics of data collected by the NS-CSHCN survey and the Texas DSHS annual outreach survey from 2018. Figures 9, 10 and 11 compare Texas and National data regarding the demographics of gender,

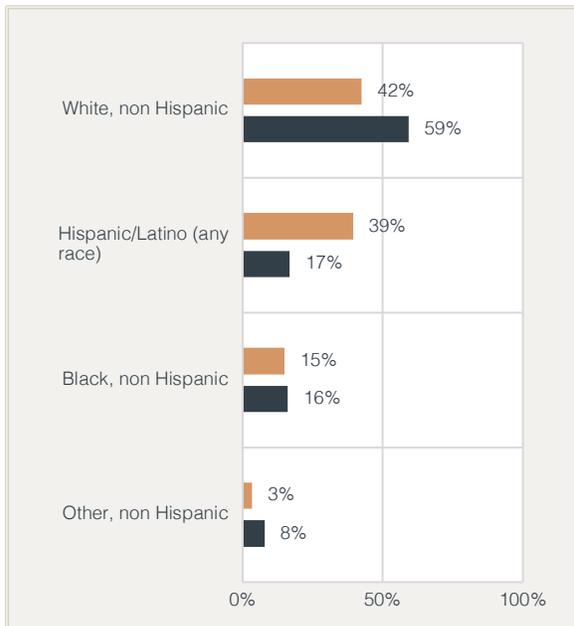
race/ethnicity, and age range of the child with special health care needs.

FIGURE 9. GENDER OF CSHCN, TEXAS & NATIONALLY



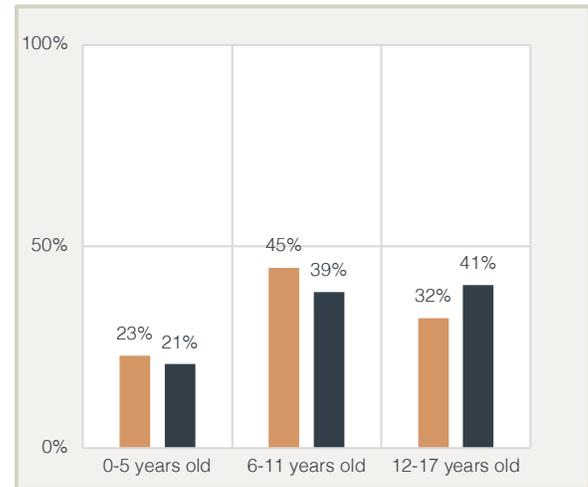
Data from 2009/2010 NS-CSHCN. Texas N=876; National N=40,172

FIGURE 10. RACE/ETHNICITY OF CSHCN, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,242

FIGURE 11. AGE RANGES OF CSHCN, TEXAS & NATIONALLY

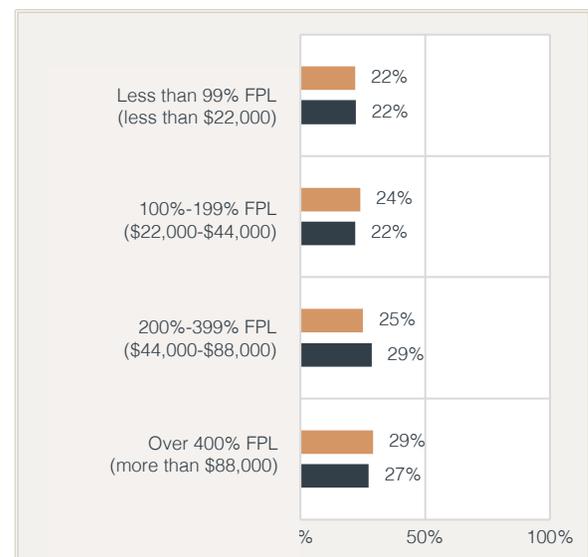


Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,242

Household Demographics

Figures 12 and 13 describe the demographics of the CSHCN household that include household income level and family structure.

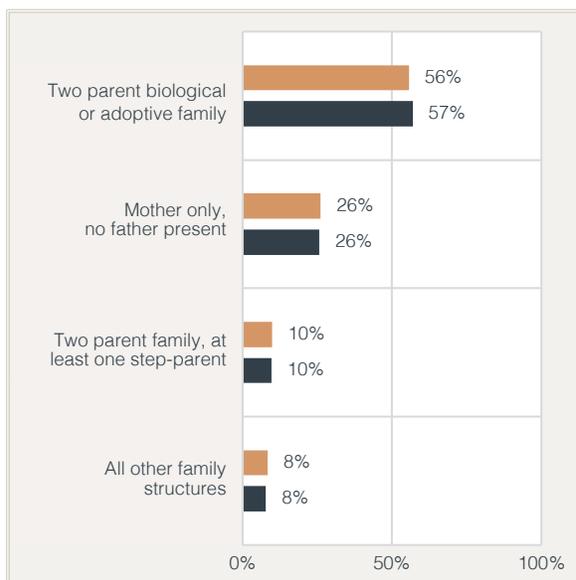
FIGURE 12. CSHCN HOUSEHOLD INCOME, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=878; National N=40,242. FPL denotes the 2010 federal poverty level.

The household dollar estimates shown in Figure 12 above are for a family of four members using the 2010 Federal Poverty Guidelines.¹⁰ The percentages of income level show that households with CSHCN span all income levels. Figure 10 below shows data of the types of family structures among households surveyed with children with special health care needs.

FIGURE 13. FAMILY STRUCTURE AMONG CSHCN, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=861; National N=39,660

Both the Texas and national datasets had similar percentages of family structures, with a two-parent household being most prevalent.

CSHCN Conditions & Demographic Summary

The purpose of presenting data on the type of conditions and demographics of CSHCN and their households is to provide some context on the types of conditions and functional challenges experienced by this population. As reiterated previously, the data presented above are all from voluntary responses collected from surveys that likely do not capture all families with

CSHCN. A snapshot of the highlights of the outcome data is provided below.

FIGURE 14. CSHCN CONDITIONS & DEMOGRAPHIC SUMMARY



- CSHCN Top Conditions: Allergies, Asthma, ADD/ADHD
- Child has 2 or more conditions
- Condition is often managed by prescription medication or requires adaptation to a functional limitation
- Behavioral and mental health conditions were rated greater severity compared to physical ones
- 45% were between ages 6-12 years old; 60% male; living in 2-parent homes of all income levels

Data from 2009/2010 NS-CSHCN.

Access to Care

Access to care is impacted by a variety of factors that often include insurance coverage, availability of providers in the community, transportation to needed care, and capacity/time for families to attend appointments, among many other factors. Particularly for the CSHCN who may require more than typical routine medical care and/or specialized services, health insurance coverage greatly impacts the child's access to

needed care in order to manage their conditions.

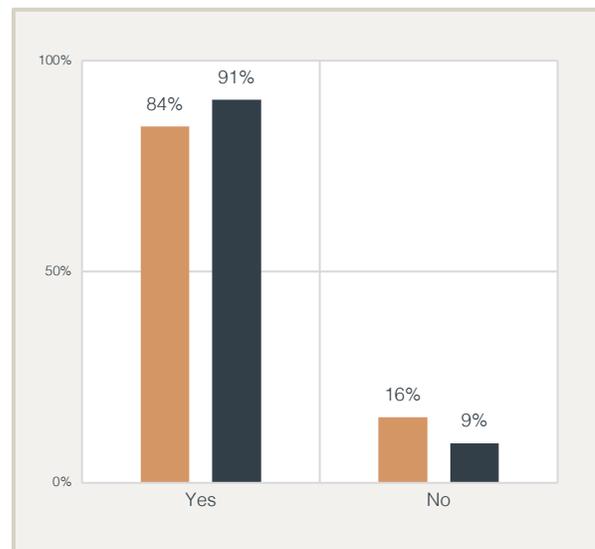
Health Insurance Coverage

There is overwhelming evidence that CSHCN with health insurance coverage experience better outcomes regarding access to care compared to uninsured children, specifically on topics of having a usual source of care, access to specialist, and avoiding unmet needs or delayed/forgone needed care.^{12,13,14,15,16} Because health insurance coverage is an important aspect for CSHCN and their families, in 1997 the Maternal and Child Health Bureau established that all CSHCN should have continuous private or public health insurance that covers a reasonable share of health care costs.¹¹

Another important factor that impacts access is the continuity of care. Gaps in health insurance coverage disrupt access to care needed for CSHCN and can have an exacerbating effect on the health and wellbeing of a child with special health care needs or medically complex needs.^{18,19} In regards to the type of health insurance coverage (public or private) on access to care, research findings on the benefits of one over the other is mixed. It is likely that many other factors affect how well public and private health insurance impacts access to care, specifically the type of insurance selected (e.g., coverage, deductibles) and availability of providers.

Figures 15 to 17 present data on health insurance coverage and costs from the NS-CSHCN data.

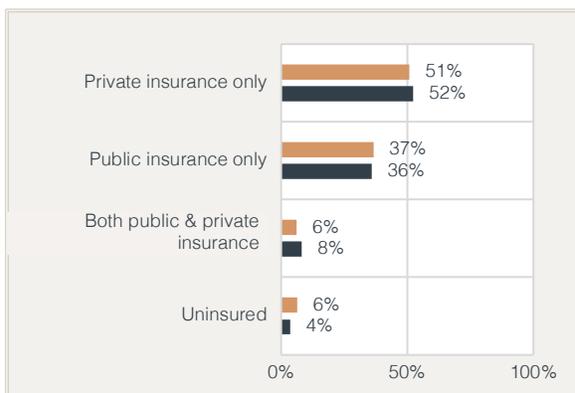
FIGURE 15. DID CHSCN HAVE CONTINUOUS HEALTH INSURANCE COVERAGE IN THE PAST YEAR?, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=876; National N=40,108

The NS-CSHCN data shows that less than one-fifth of CSHCN in Texas had a gap in health care coverage, which is a high percentage considering that health coverage greatly impacts ability to access care for this population. Figure 16 describes the type of health insurance coverage among CSHCN from the NS-CSHCN data.

FIGURE 16. TYPE OF HEALTH INSURANCE COVERAGE FOR CSHCN, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=843; National N=38,736

Nearly half of the survey respondents indicated that they are covered by private health insurance only, while a little over one-third receive public health insurance only. However, insurance coverage does not always result in actual services or specialists being available to families with CSHCN. Medical professionals and specialists must be willing to accept certain insurance options available to CSHCN, which is often a burdensome process that providers may find disincentivizing. A little over one-third of NS-CSHCN survey respondents indicated that their CSHCN's current health care insurance does not adequately cover their CSHCN's care. While more information is needed to understand why health coverage was considered inadequate, this suggests that despite having health insurance, access to the appropriate and necessary health care coverage is not guaranteed.

The NS-CSHCN also asked survey respondents about the out-of-pocket medical costs CSHCN families paid in the past 12 months, presented in Figure 17.

FIGURE 17. OUT-OF-POCKET MEDICAL COSTS AMONG CSHCN FAMILIES IN THE PAST 12 MONTHS, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=862; National N=39,641

Note: This survey collected data from 2009-2010, thus these expenses may actually be higher considering inflation and costs of services in 2020. While the majority of survey respondents indicated that out-of-pocket medical expenses were under \$250 for the past 12 months, almost one-fifth reported that out-of-pocket costs were over \$1,000, which is cost-prohibitive for many families. In another NS-CSHCN question, 24% of Texas respondents (22% of all U.S. respondents) stated that they have experienced financial problems due to costs associated with CSHCN.

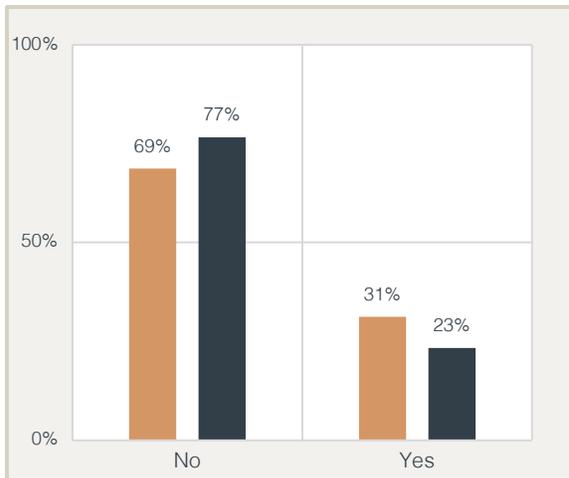
Adequate and continuous health insurance coverage is critical to ensure CSHCN are able to receive the care, services, and equipment needed to ensure their own and their entire family's wellbeing. Financial burden and high out-of-pocket costs result in families delaying or foregoing care for their CSHCN, which can result in poor outcomes. While insurance eligibility is beyond the scope of the CSHCN research project, case managers should incorporate public health insurance literacy for caregivers, ensure families have continuous health

care coverage, and assist in applying for health care coverage when possible.

Access to Providers

The following figures provide an overview of how survey respondents indicated the types of health care services sought and their ability to access providers. The overwhelming majority (over 90%) of survey respondents stated that they have one or more consistent doctor/nurse that provides care for their child. Since CSHCN experience more specialized conditions, meaningful access to a specialist provider and/or services is necessary. Figure 18 shows how survey respondents felt they were able to obtain referrals for specialty care or services for their child.

FIGURE 18. HAS CSHCN RECEIVED A SPECIALIST CARE REFERRAL?, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=256; National N=13,274

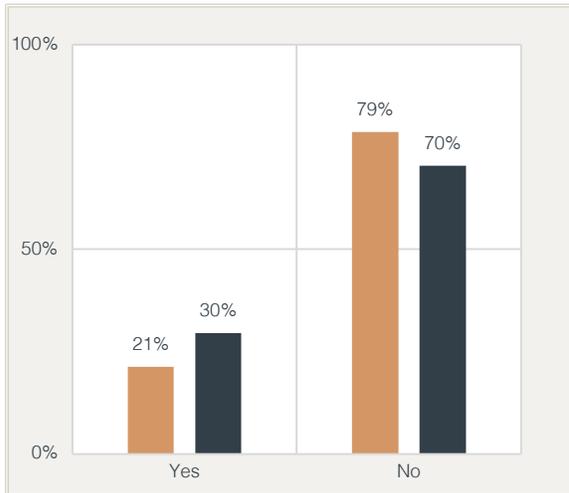
Nearly a quarter of survey respondents indicated that they had problems getting a referral for specialist care, which greatly impacts the CSHCN population who are in greater need of specialist care/services.

Access to Early Intervention & Special Education

Early intervention services are crucial in order to identify conditions and establish a care plan for CSHCN and their families. While there are many factors that impact access to early intervention, including whether or how early for which a condition can even be screened, access to early screenings is necessary for CSHCN to establish a model of care and plan for the child's future. For example, screening for a behavioral health issue that may manifest at age 12 cannot be screened for at age 2. Both Texas and nationally, 73% of survey respondents indicated that they did not receive any early intervention services for their CSHCN from the ages 0 – 2 years old (NS-CSHCN Survey Data, Texas N=54; National N=2,198). While many conditions do not manifest early enough in a child's development to be identified through early screening, the data still suggests that there may be gaps in early screening that could compromise a child's access to their highest quality of life and successful transition into adulthood.

Similarly, access to special education is often needed for CSHCN. Figure 19 shows how survey respondents indicated receiving special education services for their CSHCN ages 3 – 17 years old.

FIGURE 19. HAS CSHCN RECEIVED SPECIAL EDUCATION SERVICES?, TEXAS & NATIONALLY



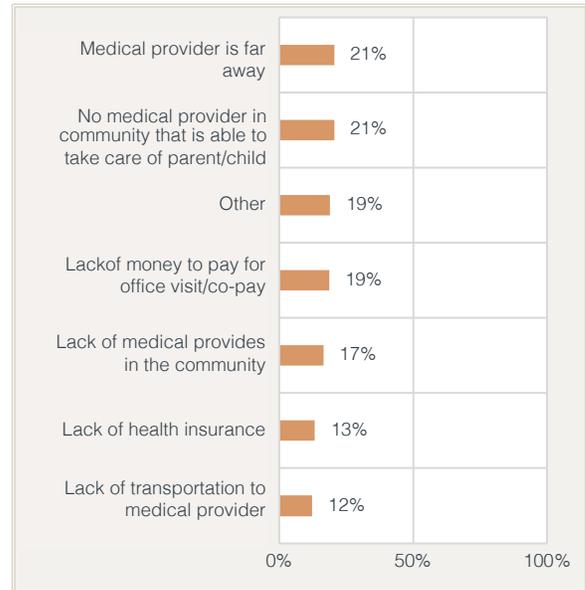
Data from 2009/2010 NS-CSHCN. Texas N=822; National N=37,868

The majority of respondents indicated that their child does not receive special education services. This also represents a gap in access to care since appropriate education for children with special health care needs is crucial for the overall wellbeing for the child and family.

Barriers to Accessing Care

The DSHS outreach survey aimed to understand barriers preventing the CSHCN population from accessing care. Figure 20 shows the barriers experienced by survey respondents.

FIGURE 20. BARRIERS TO ACCESSING CARE, DSHS OUTREACH SURVEY RESPONDENTS



Data from 2018 Texas DSHS Outreach Survey. N=735
Note: Responses classified as "Other" were not included in the report.

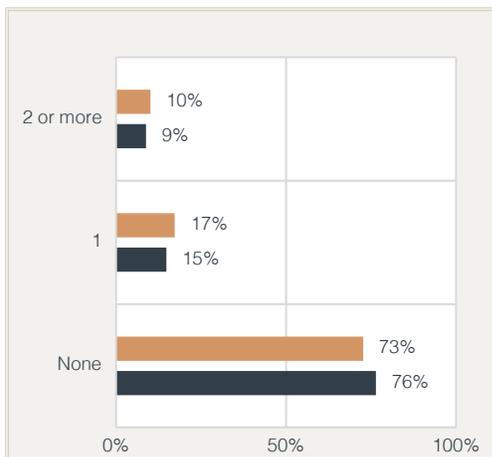
As previously discussed, the lack of providers and/or the long distance between a family and a provider greatly impacts the family's ability to receive the care they need for themselves and their child.

Care Coordination & Medical Home

One of the primary roles of case managers for the CSHCN population is to offer care coordination services to families in order to establish a medical home. A medical home is a type of model often implemented in pediatric and adult healthcare practices. The American Academy of Pediatrics supports a medical home that is "accessible, family-centered, continuous, comprehensive, compassionate, culturally effective, and coordinated across systems."²⁰ An abundance of research has shown that successful

care coordination and establishment of a medical home results in efficient service use, better health outcomes, improved satisfaction, improved family functioning, and a less burdensome financial impact.^{21,22} Unmet needs experienced by families suggests gaps in care coordination. Figure 21 shows the responses when asked about unmet needs for 14 specific health services.

FIGURE 21. UNMET NEEDS AMONG 14 SPECIFIC HEALTH SERVICES, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=863; National N=39,498

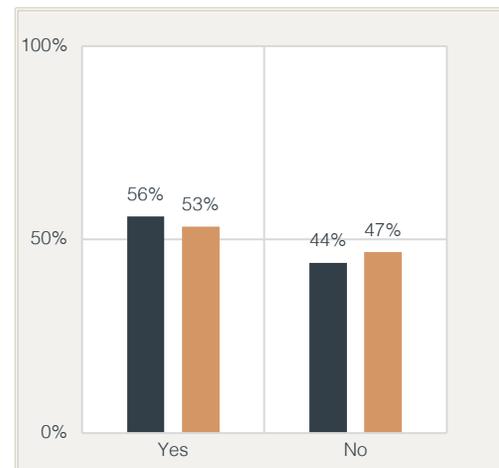
The 14 health services that were presented to survey respondents were: preventative medical care, specialist care, preventative dental care, prescription medications, occupational/speech therapy, mental health care or counseling, substance abuse treatment or counseling (ages 8-17 years only), home health care, vision care or eyeglasses, hearing aids or hearing care, mobility aids or devices (ages 3 - 17 years old only), communication aids or devices (3 - 17 years old only), and durable medical equipment.

The majority of survey respondents reported having had all of their needs met in reference to the 14 health services presented. Similarly, 93% of both Texas and National survey respondents indicated they did not

have any unmet needs for family support services (Data from 2009/2010 NS-CSHCN; Texas N=877; National N=40,145).

The NS-CSHCN and the DSHS Outreach Survey also aimed to understand how families perceived care coordination and whether they felt gaps in service. Figure 22 shows whether survey respondents considered their care coordination was effective.

FIGURE 22. DID CSHCN RECEIVE EFFECTIVE CARE COORDINATION, AMONG THOSE WHO NEEDED CARE?, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=624; National N=29,845

Interestingly, nearly half of all respondents indicated that they had unmet needs regarding their care coordination. The types of care coordination asked about were care coordination with doctors/services, communication with doctor, and communication between doctors and schools, when needed. From the 2018 Texas DSHS Outreach Survey, **only 36% of Texas families with CSHCN surveyed stated that they received care coordination services.** This data suggests that there is a large gap in providing care coordination to the CSHCN population.

The primary focus of this CSHCN project will be to develop a case management practice model specifically for CSHCN families. The Needs Assessment conducted by TXICFW will aim to better understand the strengths and areas of improvement of current care coordination practices, and how that process can be standardized when possible. The development of the practice model will utilize the medical home and care coordination standards set by various federal agencies and health care associations.

Community-based Services & Supports

Community-based organizations provide resources and opportunities for families that can greatly impact access to care and quality of life. Interestingly, there was limited recent research on the impacts of community-based services and supports specifically for children with special health care needs. Many of the community-based organizations contracted with the CSHCN Systems Development Group are organizations that serve children and families in the realm of child welfare and parenting education, which may provide some context of its possible impacts to CSHCN. For FY2020, CSCHN Systems Development Group has contracts with 16 different community organizations, referred to as CSHCN contractors in this report, who provide case management services or community resources for families. Appendix A describes the different CSHCN contractors and the services they provide.

In general, the type of community-based organizations contracted by DSHS include city/state organizations (e.g., health departments), private community-based organizations, and organizations affiliated with public universities.

Looking at the influence of community organizations on child welfare more broadly, research suggests that there are some strengths and challenges in

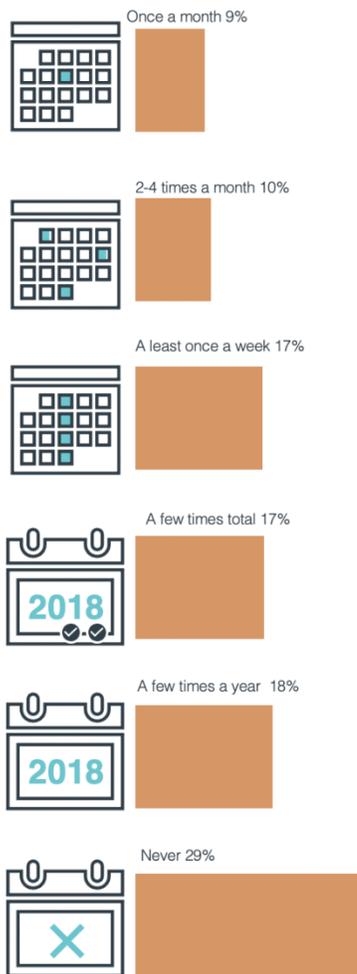
utilizing community-based organizations to provide services and supports to families. In contracting arrangements such as those employed by the CSHCN Systems Development Group, it may require more ongoing collaboration and information exchange in order to meet family needs.²³ Most child welfare service systems experience both collaboration and competition among community-organization and state agencies, referred to as co-opetition.²⁴ These contracting arrangements, however, can be mutually beneficial and help bridge gaps of service delivery in communities.

In a mixed-methods study looking at the role of community-based collaborations on the implementation of an evidence-based intervention to reduce child neglect, the data collected confirms continued support of collaborations needed to sustain evidence-based interventions.²⁵ Qualitative analysis of interviews and focus groups revealed that staff and stakeholders emphasized the importance of relationships and buy-in across multiple organizational levels as it helped to establish a collaborative infrastructure in the child welfare service system.²⁵ The lack of a formalized and planned collaborative approach may have influenced communication challenges and difficulty maintaining relationships among stakeholders.²⁵ However, the formalization of collaboration does have some challenges, such as power imbalances arising among stakeholders and lack of clarity with shared goals.²⁵ Rather than recurring meetings held simply for stakeholders to attend, this study found that successful collaborations use stakeholder meetings to provide space for co-learning, connecting, and troubleshooting.²⁵ The value of having a positive and collaborative environment was shown to have enhanced stakeholder investment and may result in positive job satisfaction.²⁵

In regards to the type of community-based services received by CSHCN, these may include community activities

that are inclusive to children with disabilities as well as respite care for caregivers. The full scope of community-based activities and supports is unknown to the TXICFW team and will be further explored during the Needs Assessment portion of this project. From existing data, the DSHS Outreach Survey aimed to understand if caregivers are able to use respite care, shown in Figure 23 below.

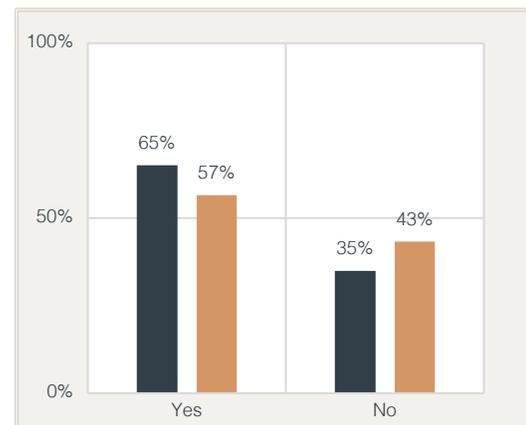
FIGURE 23. FREQUENCY OF RESPITE CARE AMONG CAREGIVERS OF CSHCN IN TEXAS, DSHS OUTREACH SURVEY



Data from 2018 Texas DSHS Outreach Survey. N=735

Nearly one-third of survey respondents indicated that they have never received respite services. It is important that caregivers are able to take care of themselves in order to best be able to care for their children. Among the caregivers that reported utilizing respite care, there was no further information given on the types of activities or reasons for which caregivers are using respite. Figure 24 shows how NS-CSHCN survey respondents felt about the ease with which they were able to access community-based services.

FIGURE 24. ABLE TO ACCESS COMMUNITY-BASED SERVICES?, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=874; National N=39,990

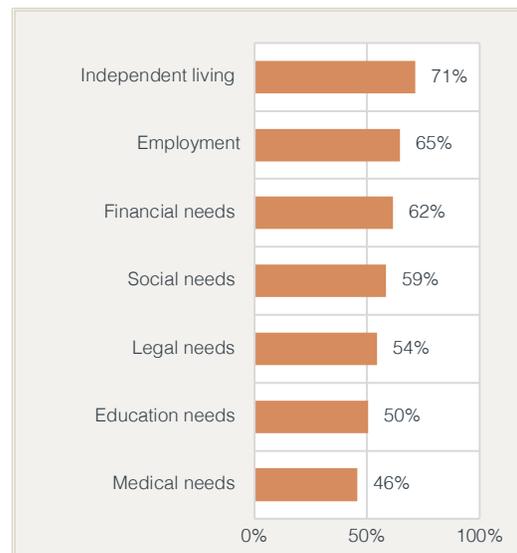
Survey respondents from Texas experienced more challenges in accessing community-based services compared to the national averages. Case managers are typically experts in identifying easily accessible resources in their communities for families. However, resources that are accessible to CSHCN may pose an additional challenge for case managers and families.

Transition to Adulthood

Multiple reputable health care organizations such as the American Academy of Pediatrics (AAP) and the American

Academy of Family Physicians (AAFP), among several others, have emphasized the importance of health care transition planning, especially for CSHCN. In 2011, these health care organizations established specific transition steps that include health care providers to: 1) Engage youth and their caregivers in assessing and developing self-care at age 18; 2) Assist youth and caregivers in identifying adult health care providers and ensure a smooth transition of medical records; and 3) Orient young adults by offering self-care assessments and skill building.²⁶ While much of the research on transition is related to the change of health care services from pediatric to adult care, there is a transition of home-based activities such as establishing routines and activities to encourage more independence. A study comparing transition planning for CSHCN and non-CSHCN found that care coordination was significantly associated with overall positive transition performance.²⁷ The American Academy of Pediatrics suggests that transition planning should begin as early as 12 years old.²⁸ While discussing transition into adulthood with caregivers may be overwhelming since they are often struggling to address their child's immediate needs, studies show the importance of these discussions and planning for the child and family's future wellbeing and quality of life. The DSHS Outreach Survey asked about seven different areas of transition. Figure 25 shows the areas for which survey respondents indicated that they have not prepared.

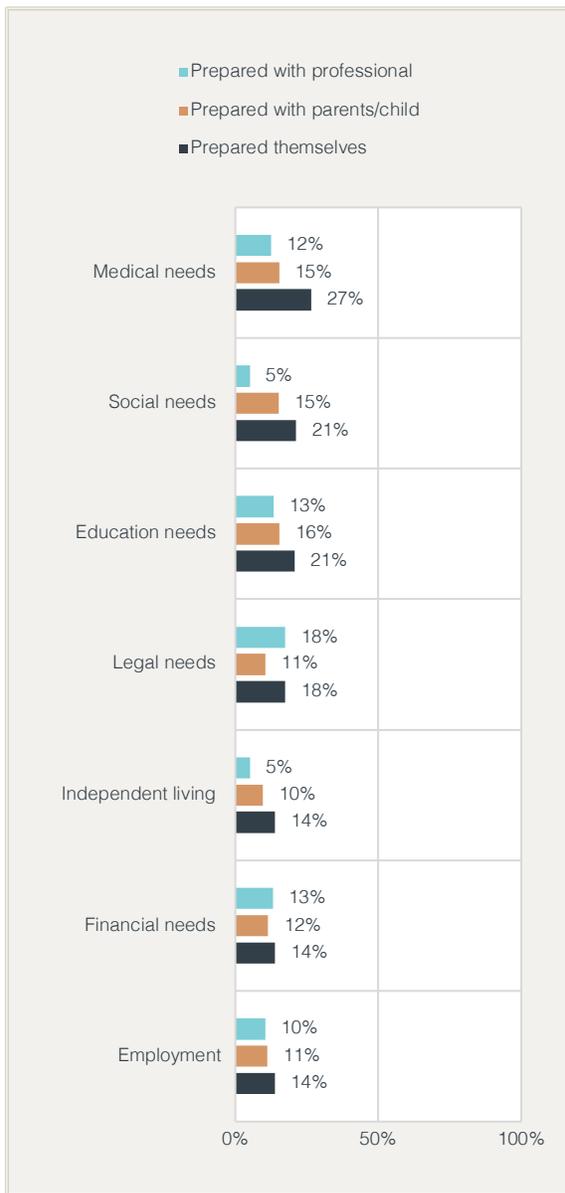
FIGURE 25. PERCENT OF RESPONDENTS WHO HAVE NOT PREPARED IN TRANSITION AREAS, DSHS OUTREACH SURVEY



Data from 2018 Texas DSHS Outreach Survey. N=735

From the DSHS Outreach Survey, 21% of respondents reported that they feel prepared for their CSHCN's transition to adulthood, 53% of survey respondents indicated that they did not feel prepared, and 26% of respondents were unsure if they feel prepared. Of those who reported feeling prepared for their child's transition into adulthood (21%), Figure 26 describes who was involved in planning for each of the seven transition areas.

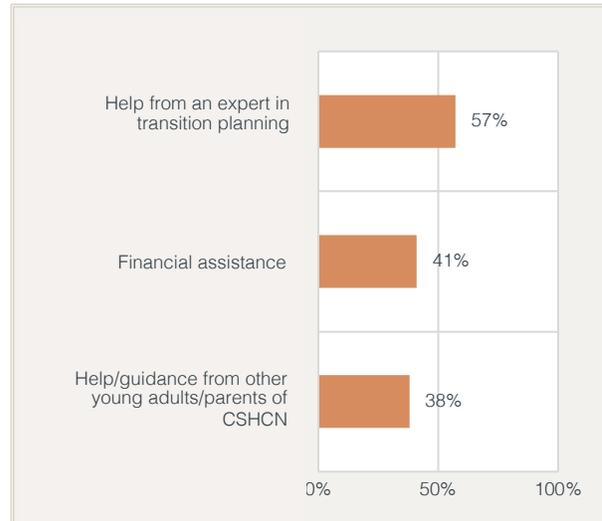
FIGURE 26. INDIVIDUALS INVOLVED IN EACH TRANSITION AREA, DSHS OUTREACH SURVEY



Data from 2018 Texas DSHS Outreach Survey. N=154

In each transition category, the survey respondent who was typically the primary caregiver was the person who led transition age planning. The DSHS Outreach Survey also asked what would be the most helpful to prepare their child for transition into adulthood. Figure 27 shows the top three responses indicated by survey respondents.

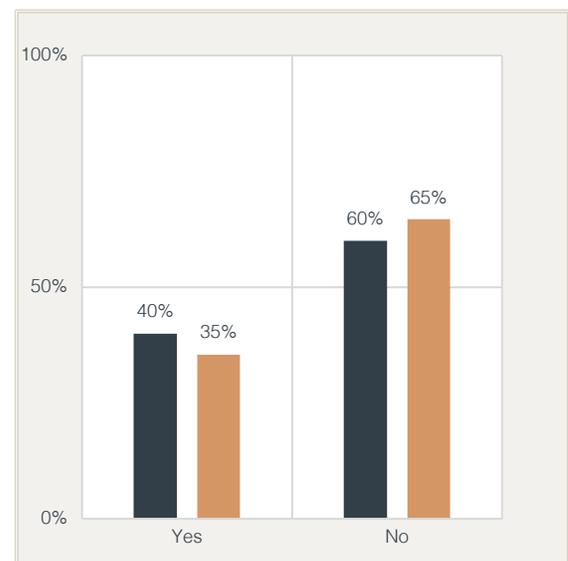
FIGURE 27. REQUESTS TO HELP IN TRANSITION PLANNING FOR CSHCN, DSHS OUTREACH SURVEY



Data from 2018 Texas DSHS Outreach Survey. N=735

The NS-CSHCN also aimed to gather perspective about the ability to transition plan, however data collected was very broad, shown in Figure 28 below.

FIGURE 28. WERE CSHCN ABLE TO TRANSITION PLAN?, TEXAS & NATIONALLY



Data from 2009/2010 NS-CSHCN. Texas N=292; National N=16,222

Similar to the DSHS data, the NS-CSHCN survey shows that transition planning is a gap experienced by caregivers of CSHCN. While it is important to ensure the primary caregiver is involved in transition planning, families could also benefit from professional support to the entire family system.



About Case Management



This section of the literature review will provide an overview of case management, including different theoretical frameworks of case management and the components of best practice case management models.

Definitions of Case Management

There is not a standardized definition of case management, nor is there a standard definition for what a case manager does. There are, however, widely accepted themes across disciplines in social sciences/social work and nursing/medical practices.

The National Association of Social Workers (NASW) defines case management as

“a process to plan, seek, advocate for, and monitor services from different social services or health care organizations and staff on behalf of a client.”^{31,32}

In a 2016 publication, the Case Management Society of America (CMSA) defines case management as

“a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote patient safety,

quality of care, and cost-effective outcomes.”^{33,34}

The Commission for Case Manager Certification (CCMC), a nationally accredited organization that certifies case managers and disability management specialists, defines case management as

“a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet the client’s health and human service needs.³⁵ It is characterized by advocacy, communication, and resource management and promotes quality and cost-effective interventions and outcomes.”³⁶

The CCMC collaborates with NASW so that social workers may obtain the specialty practice certification of Certified Social Work Case Managers (C-SWCM).³⁷

Accreditation & Scope of Case Management

In addition to CMSA and CCMC, there are multiple associations and/or accreditation agencies for case management (e.g., American Case Management Association, National Committee for Quality Assurance – Case Management Accreditations), most of which require licensure and experience in either the social work or nursing profession. Accreditation requirements for case managers is an internal decision made by organizations that employ case managers. Also, individuals may choose to seek accreditation in case management to enhance their ability to find employment or seek a promotion. The majority of these accreditation agencies stem from the medical management or nursing case management fields, and there has been an expansion in both scope and practice in recent years. According to the CMCA’s Standards of Practice for Case Management, a “number of recently enacted regulations, such as [the Patient Protection and Affordable](#)

Care Act (PPACA) and the Health Information Technology for Economic and Clinical Health (HITECH) Act, have resulted in the emergence and legitimization of case management as a necessary care delivery model and intervention.”³³ While the provision of services through insurance providers is beyond the scope of the CSHCN project, it is incumbent upon any case manager to help the client navigate health insurance or lack thereof.

Both CMSA and CCMC are primarily focused on medical and nursing case management. However, there are observable similarities between both the social sciences and the medical fields’ approach to case management, such as collaboration and advocacy across agencies on behalf of a client. Of note, social science definitions tend to use the verbiage “case management.” Medical and nursing publications tend to vacillate between “case management,” “care coordination,” and “care management,” and many publications further differentiate between those terms. There does not appear to be national or federal oversight or preference among these varying accreditation agencies. For the purpose of this literature review, the term “case management” will be exclusively used.

Philosophy of a Case Management Model

This section will discuss two main philosophies of case management models, the social sciences/social work philosophy and the medical/nursing philosophy.

Social Sciences/Social Work Philosophy

A case management practice model serves as a centralized place where values are acknowledged and clear pathways toward goals are created. A case management practice model should be endorsed by an organization’s leadership and community stakeholders, while serving

as a direct guide for frontline staff in their work with families. Successful models should be transparent and inclusive of the child and family at every level. Frontline staff should feel empowered by having universal goals and beliefs that support evidence-based interventions, allowing for their flexibility and expertise to be used in crafting individualized services for children and families. A case management practice model should define an organization’s expectations and standards for case documentation. Case managers should have the ability to clearly indicate what services are planned and operationalized, and supervisors should be able to recognize an agency’s universal goals and beliefs within case documentation and outcomes. While an organization’s policies and procedures should align with its case management practice model, the practice model itself should teach just that: practice skills that can be honed and followed for successful work with children and their families.

According to the Child Welfare Policy and Practice Group,³⁸ a practice model can:

- Provide a moral authority for practice
- Force attention on how children and their families experience services and interventions
- Promote consistency in approaches throughout a system
- Guide the content of an organization’s policy
- Inform training in an organization
- Reshape employee performance expectations
- Help shape organizational design

A practice model also sets the expectations and processes for case documentation. Consistent, thorough documentation is important with respect to the following⁹:

- Clear communication
- Continuity of care

- Service planning
- Evaluation
- Service reimbursement
- Accountability
- Legal implications

Medical/Nursing Framework Philosophy

The Center for Case Management Certification suggests that case managers should have a model that allows for direct communication among the case manager, the client, the payer, the primary care provider, and other service delivery professionals.³⁵ Case management approaches should focus on client wellness and autonomy through advocacy, assessment, planning, communication, education, resource management, and service facilitation, ultimately to achieve optimum value and desirable outcomes for all stakeholders.³⁵ Treadwell et al. explain that “healthcare professionals must have a multidimensional case management approach that is highly personalized and addresses all segments of the health care system, medical issues, behavioral issues, and social

barriers.”⁴⁰ Children with complex conditions are often seen by multiple providers, and “fragmented interaction among these providers leads to inconsistent and poorly managed care.”⁴¹ Chen et al. explain that the “needs of patients with chronic conditions are not adequately met by the acute care system; they require a defined management plan that includes regular assessment, defined interventions, and well-coordinated communication among patients, caregivers and the primary care team.”⁴¹ It is suggested that the structure of an evidence-based model addresses the need for education and support of families through alignment of both treatment and communication.⁴⁰

In summary, there are observable similarities between both the social science and the medical fields’ approach to case management, including the need to provide assessment, service planning, and collaboration among service providers. Both approaches are child and family-centered and strive for positive outcomes. Table 2 provides a high-level summary of the social science/social work and medical/nursing case management philosophies.

TABLE 2. SUMMARY OF CASE MANAGEMENT PHILOSOPHIES

SOCIAL SCIENCE/ SOCIAL WORK CASE MANAGEMENT PHILOSOPHY	MEDICAL/ NURSING CASE MANAGEMENT PHILOSOPHY
<p>A case management practice model serves as a centralized place where values are acknowledged and clear pathways toward goals are created.</p> <p>This includes assessment, engagement, teaming, planning, collaboration, monitoring, evaluation, and termination.</p>	<p>Case management should focus on client wellness and autonomy through advocacy, assessment, planning, communication, education, resource management, and service facilitation, ultimately to achieve optimum value and desirable outcomes for all stakeholders.</p>

Types of Case Management Practice Models

Some case management practice models are program or intervention specific, serving as a roadmap for a precise function. More broadly, and more commonly, case management practice models serve as basic sets of principles and approaches that inform an organization's work. This broader definition crosses both social services/social work models and nursing/medical models. A case management model should be specific enough to inform frontline workers about their duties and expectations, but broad enough to encompass supervisory and leadership tasks that include self-defined goals, values, organizational structure and stakeholder/community relationships.

Brokerage Case Management (Social Services/Social Work)

In a brokerage case management model, the case manager provides very little direct service to the client. Instead, they serve as a link between a client and community resources. The focus is on assessing needs, planning a service strategy, and connecting clients.

Clinical Case Management (Social Services/Social Work)

In a clinical case management model, a clinical care provider serves as the case manager and is likely a licensed social services or medical provider. This model recognizes that many clients face barriers to services that reach beyond simple questions of access. While there are common components to clinical case management, such as engagement, assessment, and planning, there are also clinical components, including intermittent individual psychotherapy, teaching independent living skills, and

psychoeducation about psychiatric and medical disorders.⁴²

Strengths-based Clinical Case Management (Social Services/Social Work)

In a strengths-based clinical case management model, case managers focus on empowering clients and their families. Case management and clinical services focus on creating client opportunities for growth, education, and skill development. The strengths-based case management model steps away from the perspective that the clinician is the expert on the client's needs. It encourages the client to take the lead in identifying their own needs, take control over the search for resources and services to address those needs, and view the community as a resource instead of a barrier to success instead.

The Chronic Care Model (Medical/Nursing Services)

The aim of the Chronic Care Model is to transform the daily care for patients with chronic illnesses from acute and reactive to proactive, planned, and population-based. It is designed to accomplish these goals through a combination of effective team care and planned interactions; self-management support bolstered by more effective use of community resources; integrated decision support; and patient registries and other supportive information technology. These elements are designed to work together to strengthen the provider-patient relationship and improve health outcomes.^{40,43} The model also acknowledges the influences of the community and the healthcare system on ultimate patient outcomes, which is an important part of coordinating across school standards, neighborhood and state resources as well as navigating the health system for access and necessary services.⁴⁰

Continuum of Healthcare Model (Medical/Nursing Services)

The Continuum of Healthcare Model focuses on a patient centered model of delivery, and the case management process is viewed within a circular model of financial, ethical and legal, social support, and care providers.¹⁰ The CMSA Standards of Practice for Case Management supports this model and states that the philosophy targets “optimum client wellness and function through communication, advocacy, education, resource identification, and facilitation of services to benefit the client, support system, healthcare delivery system and reimbursement.”³³

Best Practice in Case Management Model Development

The two overarching parts of building a successful case management model include development and implementation. There are various approaches to implementing a practice model that are dependent on an organization’s structure, goals, values, budget, timeline, etc. McCarthy and the National Child Welfare Resource Center for Organizational Improvement explain that

“when implementing a practice model, the principles should guide the approach toward working with individual children and families as well as the process for developing the practice model. Furthermore, when implemented, these principles should be integral to all agency operations and external relationships.”⁴⁴

This section will not provide an extensive review of implementation science but will focus on different types of case management models that are inclusive of both development and implementation.

Inclusion of Internal & External Stakeholders

Existing literature shows that case management models are best developed by bringing together internal staff, external staff, key stakeholders, and the population served (children and families) in an inclusive process.^{33,44,45} This is to ensure that every component of the model is endorsed and valued by frontline staff through to executive management, and well received by the community.

According to the National Child Welfare Resource Center for Organizational Improvement, the development and implementation of a practice model should include an agency and its internal and external stakeholders in a process to:

- confirm the agency’s overall vision;
- identify the basic principles and values for the practice model;
- set goals and desired outcomes that align with the principles;
- describe the core intervention components/skills it wants to practice, setting standards for skills, behaviors and actions of workers, supervisors, and managers that will reflect the agency’s principles;
- provide the resources and supports needed to implement the practice model; and
- evaluate fidelity to the practice model, the implementation process, and outcomes for children youth and families.⁴⁴

The National Child Welfare Resource Center for Organizational Improvement’s guide for developing and implementing child welfare practice models states that, regardless of which specific principles are selected by an agency, the process should always: 1) involve multiple stakeholders (internal, external, including families and youth); 2) focus on what the agency and community believe should guide the work; and 3) acknowledge the selected principles as the agency’s value base.⁴⁴

In both medical and social sciences/social work case management model development, the inclusion of internal and external staff, stakeholders, and clients is paramount in order to establish goals, visions, and outcomes. There are also overlapping themes about the need for practice to be collaborative, inclusive, and patient or family-centered.

Cultural Humility & Cultural Responsiveness

Best practice case management model development literature consistently highlights the imperative that models must be culturally sensitive and culturally responsive. The use of a family-centered approach toward case management should inherently be sensitive to one's culture because the family is involved in their own case planning. The National Child Welfare Resource Center for Organizational Improvement suggests that, on a practice level, a case management model should use a family-centered approach, define culture broadly, involve cultural brokers, and review current data.⁴⁴ Defining culture broadly means thinking beyond race/ethnicity to include religion, geographic regions, socioeconomic status, class, sexual orientation, disability, etc. Thinking broadly about culture enables social workers to recognize and respond to multiple cultural variables, even among racially homogeneous groups.⁴⁶ Cultural responsiveness is the concept that, through assessment, a case manager first learns about cultural nuances and then approaches service planning in a manner responsive to a family or community.

Cultural humility, as opposed to cultural competence or cultural sensitivity, is a more recent diversity concept in social sciences/social work and nursing/medical practices that assumes one can never achieve true competence in another's culture.⁴⁷ Instead of achieving competence or simply approaching culture through a sensitive lens, cultural humility involves a change in overall perspective and way of life.⁴⁷ In a multicultural world

where power imbalances exist, cultural humility is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals.⁴⁷ With a firm understanding of the term, individuals, health care providers, and communities will be better equipped to understand and accomplish an inclusive environment with mutual benefit and optimal care.⁴⁷

Acuity of Need & Dosage of Case Management

Part of developing a best practices case management model is defining how and what needs to be measured, monitored, and evaluated. In case management, these "what" principles are commonly referred to as acuity and dosage. The following information is adapted from a previous TXICFW report.⁴⁸

Acuity: Patient acuity is "the severity of illness or client condition that indicates the need for the intensity of the subsequent [case management] intervention."⁴⁹ In other words, acuity is the intensity of clients' needs, which can then be matched to the appropriate level of intensity of case management that will be performed to meet those needs. Patient acuity serves as a proxy for the complexity of case management activities that are needed. In the child maltreatment prevention field, acuity could relate to the number of risk and protective factors exhibited by different families.

Dosage: It is important to measure the dosage of case management activities because too little or too much of a "dose" may not produce the desired effects on outcomes, may waste resources nonproductively, or even produce harmful outcomes.⁵⁰ Dosage offers a more precise description of case management that goes beyond simply the number of hours of service delivery. Huber et al. developed a conceptual model of intervention dosage in case management, defined by the following core elements:

1. Amount: The quantity of the target activity in one episode.
 2. Frequency: The rate of occurrence or repetition.
 3. Duration: How long the activity is available over time.
 4. Breadth: The number and type of possible intervention components or activities.⁵⁰
- Guidelines/Expectations for Case Documentation
 - Resources

**Some models proposit that vision is the first step that guides the selection of values, principles, and outcomes. Other models have these categories separate or use the terms interchangeably.*

In addition to these common components of case management models, research shows that there are also stages of case management that are typically represented among models. These stages are not meant to be linear, nor are they meant to be a one-time occurrence. Each of these is a continuous process, often interlinking with one or more of the other stages.

Components of Best Practice Case Management Models

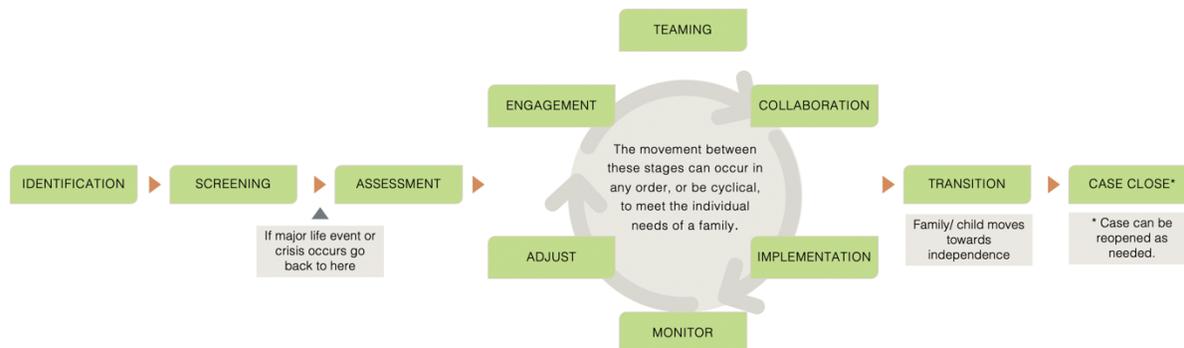
Literature about best practices in case management includes evidence-based examples of models with varying elements such as 1) core components, 2) guiding practice principles, and 3) stages within case management. Despite the specific design or flow of various practice models, the following components are typically found.

Common Components of Case Management Models

- Description, Purpose, Introduction
- Desired Outcomes
- Guiding Principles/Values/Vision/Mission*
- Core Competencies/Skills for staff
- Interventions/Tools
 - Assessments (Medical, Social, Cognitive, Behavioral, Functional)
 - Plans of Service
 - Interviewing techniques
 - Case Map
 - Genograms, Ecomaps
 - Crisis Intervention
- Case examples
- Continuous Quality Assurance Protocol

Common Stages in Case Management Models

FIGURE 29. COMMON STAGES IN CASE MANAGEMENT



In addition to the common components and stages, research shows some common practice principles, particularly among case management models for children and families. The most common practice principles are outlined below.

Common Practice Principles

The following bullet points are a list of common practice principles for children and families that include:

- family-centered practice (endorsed by children’s bureau)
- community-based services (endorsed by children’s bureau)
- individualizing services to meet the unique needs of children and families (endorsed by children’s bureau)
- child-focused (endorsed by children’s bureau)
- collaborative (endorsed by children’s bureau)
- culturally responsive (endorsed by children’s bureau)
- outcome oriented (endorsed by children’s bureau)
- the importance of focusing on child social and emotional well-

being to improve outcomes (endorsed by children’s bureau)

- coordinated at both the system and service delivery levels
- involve families and youth as full partners
- emphasize early identification and intervention

Note: Common Practice Principles are from Guide for Developing and Implementing Child Welfare Practice Models. National Child Welfare Resource Center for Organizational Improvement.⁴⁴

The above sections represent the most common elements among case management models including: 1) core components, 2) guiding practice principles, and 3) stages within case management. The specific design and flow of models varies depending on the size of the intervention and population served. The case management process is cyclical and recurrent, rather than linear and unidirectional. For example, key functions of the professional case manager, such as communication, facilitation, coordination, collaboration, and advocacy, occur throughout all the

steps of the case management process and in constant contact with the client, client’s family or family

caregiver, and other members of the interprofessional health care team.

Conclusion

This literature review aims to understand the scope of conditions experienced by CSHCN, the foundational components of family-centered, accessible, high-quality care coordination specific to CSHCN, and challenges faced by CSHCN and their families. By compiling and analyzing existing data surveyed among the CSHCN population from federal and state implemented surveys, this literature review will help inform the development of the Needs Assessment for the CSHCN population receiving case management services from DSHS to gather more in-depth information from practitioners and families, that with further tailor case management practices to the CSHCN population in Texas.

Aligning with the federal domains of CSHCN, the Needs Assessment conducted by the TXICFW team will aim to gather information from providers, stakeholders, and caregivers from the same five domains of Identification, Screening, Assessment Referral; Access to Care; Care Coordination; Community-based Services and Supports; and Transition Services.

Next Steps: Incorporating Research into the Case Management Practice Model

In addition to informing the development of the Needs Assessment, this literature review will also be used to as a framework for the development of the case management practice model, specifically the five domains of the National Standards for CSHCN and the core components of case management (e.g., family-centered, culturally-adaptive, and collaborative). The findings collected from the Needs Assessment will further

inform the case management practice model, including specific processes and protocols unique to case management implementation in Texas.

By incorporating the research from these three areas of: 1) National Standards of CSHCN; 2) best practices on case management; and 3) the Needs Assessment of CSHCN case management services in Texas, the case management practice model will appropriately reflect the best practices identified nationally and within the scope of how the CSHCN population is served in Texas. As discussed in the CSHCN Project Background section in the beginning of this report, the goal of the case management practice model is to leverage the strengths already implemented by CSHCN case managers in Texas while ensuring that these practices are aligned with known best practices research of the CSHCN population and best practices in case management model development.





Needs Assessment

Needs Assessment of CSHCN Case Management in Texas



This section of the report details the Needs Assessment of CSHCN case management in Texas that was designed and conducted by TXICFW. An overview of the topics covered in this Needs Assessment is outlined below:

- Research Questions
- Design and Methodology
- Outcomes of Needs Assessment Data
- Findings of Needs Assessment Data
- Limitations
- Recommendations

Note: The Outcomes section presents a summary of the demographics of Texas state agency collected data that was provided to TXICFW. The Findings section presents the Needs Assessment data and offers interpretations of the data collected by TXICFW.

Research Questions

This Needs Assessment was guided by the following research questions with the goal of understanding how case management services are provided to CSHCN families in Texas by DSHS regional staff and CSHCN contractors.

1. What are the processes and protocols for providing case management to CSHCN?

2. What are the strengths and challenges in how regions are providing case management services to CSHCN?
3. What are the issues that need to be considered in improving each of these 5 domains of CSHCN care (Federal Standards of CSHCN)?
 - i. Identification, Screening, Assessment, and Referral
 - ii. Access to Care
 - iii. Medical Home and Care Coordination
 - iv. Community-based Services and Supports
 - v. Transition to Adulthood

Design & Methodology

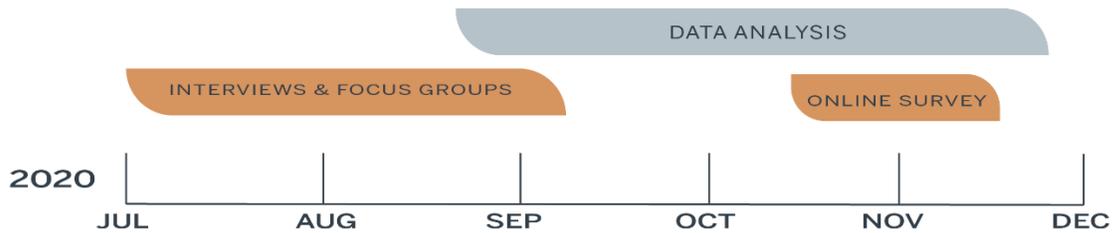
A mixed-methods study design was used for the Needs Assessment that included qualitative data collection and quantitative data collection. A brief description of the types of data collected is below.

Qualitative Data: Interviews and focus groups with staff/stakeholders who serve CSHCN and caregivers of CSHCN.

Quantitative Data: One online survey for caregivers and staff/stakeholders. Questions were displayed dependent upon whether the participant indicated that they were CSHCN staff or caregiver of CSHCN.

The purpose of gathering data through both quantitative and qualitative methods was to capture a more holistic understanding of the experiences of families with CSHCN and the staff who serve them. Mixed-methods study designs provide the opportunity to validate findings from quantitative and qualitative data or highlight diverging experiences among the two data sources. Interviews are particularly valuable in order to gain a deeper understanding of the nuances of

FIGURE 30: NEEDS ASSESSMENT TIMELINE



and challenges, that are difficult to capture in survey questions. Figure 30 describes the timeline for data collection and analysis.

Qualitative Data Collection: Interviews & Focus Groups

TXICFW conducted interviews and focus groups with caregivers, staff, and stakeholders representing almost every region in Texas in order to gather an understanding of shared strengths as well as unique challenges of current case management practices across regions. Participation in interviews and focus groups was voluntary. Within each region and organization, participants were assigned together according to their job role and level within the chain of command, creating a safe environment for open dialogue. For example, managers, supervisors, and team leads were interviewed separately from case managers in each region. All interviews and focus groups for staff were conducted via the video conference platform Microsoft Teams, and interviews with caregivers were conducted on either Microsoft Teams or Zoom, depending on their preference. Both Microsoft Teams and Zoom have video and phone capabilities.

Interview & Focus Group Recruitment Process

TXICFW coordinated with the CSHCN Systems Development Group and the Regional and Local Health Operations CSHCN Group to gather contact

information of all regional staff and CSHCN contractors to identify participation interest and schedule interviews and focus groups. This section outlines the recruitment process to gain participation in the qualitative data collection portion of the Needs Assessment.

All staff, stakeholders, and caregivers who participated in interviews and focus groups completed a short online survey (pre-interview form) that included the consent and collected basic demographic information. Participants were able to skip any demographic question they preferred not to answer. The questions in the pre-interview form are located in Appendix B, and interview guides are located in Appendix C. The recruitment process for interviews and focus groups was different for staff/stakeholders and caregivers. The recruitment process for each participant type is outlined below.

Recruitment Process: Staff & Stakeholders

1. **Introduced CSHCN Project and TXICFW team**
TXICFW developed CSHCN Project Introduction Slides and Introduction Video providing an overview of project goals, project activities, and an introduction of the TXICFW team.
2. **Received CSHCN staff e-mails to TXICFW team**
TXICFW received a list of names and e-mails of all

Regional Specialized Health and Social Services (SHSS) Managers, DSHS regional case managers, CSHCN contractor supervisors/managers, and direct service staff at CSHCN organizations. Staff were also able to refer any other stakeholders/advocates who they felt would be interested and whose voice would be important to capture as part of the Needs Assessment.

3. Gained participant interest and set up interview groups from primary staff contacts

The TXICFW team e-mailed managers (CSHCN contractor managers and SHSS managers) and case managers to gain interest and a better understanding of the types of different interviews and focus groups appropriate for each region.

4. Scheduled interviews

The TXICFW team distributed a Calendly link (online scheduling platform) to each interview group allowing them to select a day/time to schedule an interview with a TXICFW team member. After scheduling, participants were redirected to complete the pre-interview form that included the consent and demographic questions.

5. Conducted interviews

The TXICFW team reviewed the consent again prior to the interviews and focus groups. Interviews and focus groups were conducted via video or phone using Microsoft Teams. Interviews and focus groups were securely recorded, and the participants were notified when recording was turned on and off. In order to preserve the quality of recordings, there was a limit of 4 participants on focus groups.

*Recruitment Process:
Caregivers*

1. Received recommendations of caregivers from case managers

In an effort to minimize the burden on staff and families, the TXICFW team received recommendations of caregivers who would be willing to participate in interviews. The TXICFW team encouraged CSHCN staff to suggest caregivers who represent diverse background in race/ethnicity, caregiver's age, primary language spoken, health care coverage, household income, and child's CSHCN diagnoses.

2. Case managers gained caregivers' consent to share contact information to TXICFW

Case managers were asked to share information about interviews to families, including the \$25 gift card incentive for their participation in an interview. After receiving interest from the caregiver, case managers were asked to complete a short form. This form indicated they received consent from the caregiver to provide contact information to the TXICFW team, including caregiver's phone number, e-mail, and preferred language for the interview (English or Spanish).

3. Scheduled interviews

A TXICFW team member contacted the caregiver by email or phone to schedule an interview and request that the caregiver complete the pre-interview form, inclusive of consent and demographic questions.

4. Conducted interviews

Interviews were conducted using Microsoft Teams or Zoom, through either platform's phone or video capabilities. Interviews were conducted in either English or Spanish, depending

on the caregiver's language preference. Interviews were securely recorded, and the participant was notified when recording was on and off.

- 5. Distributed incentives**
After the interview, the TXICFW team member confirmed the caregiver's email address for receipt of their \$25 e-gift card redeemable at a variety of stores (e.g., Amazon, Walmart, Target, etc.).

Qualitative Data Analysis

The following steps describe the data analysis process after interviews and focus groups are conducted.

- 1. Transcribed audio recordings**
Once interviews and focus groups were recorded, the audio recordings were transcribed using GMR Transcription, a third-party secure transcription service used by TXICFW. Audio files were uploaded to GMR Transcription, which transcribed the recordings verbatim in either English or Spanish and then placed the transcription into a Microsoft Word document.
- 2. Coding: Thematic Analysis**
TXICFW employed thematic analysis methods to analyze qualitative data by developing a coding scheme of major themes and applying codes to statements in the transcripts. Coding was completed using Dedoose, a secure, qualitative analysis cloud-based platform.
- 3. Coding Analysis**
After all transcripts were coded and reviewed by the TXICFW team, all codes were further analyzed and reorganized in Microsoft Excel. The reorganization of codes and excerpts is to better understand the frequency of themes observed.

Quantitative Data Collection: Online Survey

Quantitative data was collected through an online survey that was completed by CSHCN staff, stakeholders, and caregivers. As with interviews, participation in online surveys was voluntary. Individuals were welcome to participate in both an interview and the online survey. Caregivers who were not DSHS employees or worked for an organization contracted DSHS received a \$15 gift card.

Online surveys included questions that were similar in theme to the interview guides, such as:

- CSHCN diagnoses
- Case management experience
- Access to care
- Community-based services and supports
- Planning: Disaster and transition to adulthood

The questions in the online survey were developed by the TXICFW team based on best practices research on CSHCN and case management. There are a few questions that were adapted from validated surveys and one question that was used in the CSHCN survey implemented by Utah Department of Health.⁵

Online Survey Recruitment Process

The online survey link was emailed to DSHS staff contacts, CSHCN contractor contacts, and Practice Model Advisory Group participants who helped widely distribute the survey to staff, stakeholders, and caregivers. The online survey collected responses for two weeks. The TXICFW team sent out 2 reminders to the online survey distribution contact list.

Quantitative Data Analysis

The online survey data was analyzed using SPSS statistical analysis software. Descriptive statistics were conducted to examine online survey data.

Needs Assessment Outcomes: State Collected Data

This section of the report presents two types of outcome data specific to the CSHCN programming implemented by DSHS: 1) Data collected by DSHS and HHSC, and 2) Needs Assessment data collected by TXICFW from CSHCN staff and caregivers who voluntarily participated in interviews/focus groups and the online survey.

CSHCN Programming Data from the State of Texas

TXICFW requested data from DSHS and HHSC in order to understand what data is currently being collected from families and to gain a sense of the clientele receiving CSHCN programming. TXICFW received three types of data from DSHS and HHSC, outlined below:

- 1. Data from CSHCN Contractors**
The DSHS CSHCN Systems Development Group collects data from their CSHCN contractors (case management contractors and family services community resources contractors) via quarterly reports from each contractor.
- 2. Data from Regional Case Managers**
The DSHS Specialized Health and Social Services collects data from regional staff through a database. Regional staff input data into this database, known as TWICES.
- 3. Data from the CSHCN Services Program**
The Texas Health and Human Services Commission (HHSC) is responsible for determining

eligibility for the CSHCN Services Program. The CSHCN Services Program is the benefits program that covers health care costs and services for children who meet qualifications. See Table 1 for these eligibility requirements.

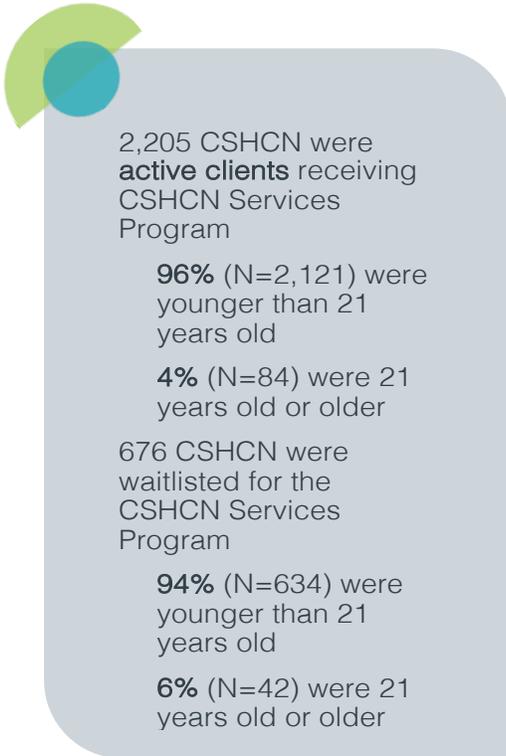
State Collected Demographic Data

The information in this section presents demographic information from fiscal year 2020 from the three different data sources: 1) Data from CSHCN contractors, 2) Data from DSHS regional staff, and 3) Data from HHSC's CSHCN Services Program. It is important to note that there may be duplicated clients in the data, as it was not possible to know the different services clients received.

Number of CSHCN Clients Receiving Services

While this project is focused on general case management services for CSHCN families, it is also valuable to understand the number of clients receiving benefits and services specifically from the CSHCN Services Program. Among DSHS regional staff, case managers typically help CSHCN families apply for the CSHCN Services Program upon referral of a new family. Among CSHCN case management contractors, it was not clear whether they routinely helped families apply for the CSHCN Services Program. Figure 31 describes CSHCN clients who were waitlisted or received services from the CSHCN Services Program in FY2020. Note: The data is by each CSHCN client. There may be multiple CSHCN clients in each family.

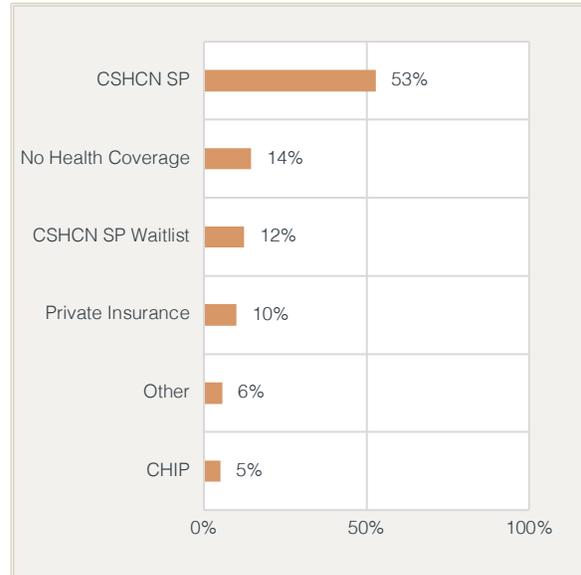
FIGURE 31. CLIENTS IN CSHCN SERVICES PROGRAM OR ON THE WAITLIST, FY20



Data Source: HHSC CSHCN Services Program Data, FY20.

Among DSHS regional staff, **a total of 2,343 CSHCN clients were provided case management services in FY2020.** Figure 32 describes the total number of CSHCN clients who received case management services from DSHS.

FIGURE 32. CSHCN CLIENTS RECEIVING CASE MANAGEMENT SERVICES FROM DSHS REGIONAL STAFF BY HEALTH INSURANCE TYPE, FY20



Data Source: FY20 DSHS Regional Office Data. Note: CSHCN SP denotes the CSHCN Services Program.

Among the CSHCN contractors that provide case management services, **a total of 1,004 CSHCN clients received case management services from 8 different organizations across the state in FY20.** In addition to case management, DSHS contracted with 14 organizations across the state to provide family support and community resources (FSCR) to CSHCN families. Resources and support range from basic needs and funds to educational sessions. In FY20, **4,715 CSHCN clients received resources and support from these organizations.**

CSHCN contractors also collected data on the types of services provided to families. Figure 33 describes the types of case management services provided by CSHCN contractors. Figure 34 describes the types of services and resources provided among CSHCN contractors delivering FSCR.

FIGURE 33. TYPES OF CASE MANAGEMENT ACTIVITIES & NUMBER OF SESSIONS PROVIDED TO CSHCN FAMILIES BY CSHCN CONTRACTORS, FY20

CASE MANAGEMENT TASKS	NUMBER OF SESSIONS
TRANSITION TO ADULTHOOD SERVICES	1,465
ASSISTED WITH EMERGENCY PREPAREDNESS	1,183
PROVIDING EDUCATIONAL SUPPORT	563
ASSISTED WITH HEALTH INSURANCE APPLICATIONS	477
ASSISTING WITH MEDICAID WAIVER APPLICATIONS	430
PREPARING FOR MEDICAL NEEDS AS AN ADULT	345
PREPARING FOR INDEPENDENT LIVING AS AN ADULT	343
FINDING BEHAVIORAL/MENTAL HEALTH RESOURCES	305
HIGHER EDUCATION PLANNING	262
FINANCIAL EDUCATION	261
WORKFORCE DEVELOPMENT PLANNING	254
FINDING DENTAL SERVICES	212

Data Source: FY20 DSHS CSHCN Contractors Quarterly Reports.

FIGURE 34. TYPE OF SUPPORT SERVICES PROVIDED BY FSCR-CONTRACTED ORGANIZATIONS, FY20



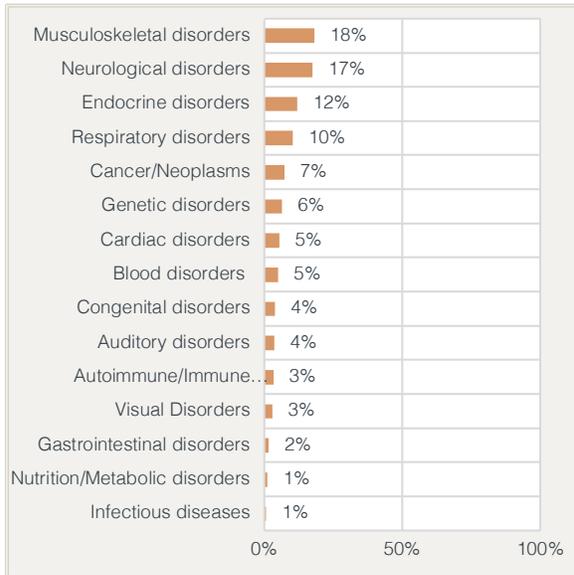
- 227 scholarships/stipends provided for CSHCN families
- 103 education sessions on transition age planning
- 7,364 hours of respite provided

Data Source: FY20 DSHS CSHCN Contractors Quarterly Reports.

CSHCN Diagnoses

The CSHCN Services Program data was the only data source provided to TXICFW that collected the types of diagnoses among CSHCN clients. CSHCN diagnoses data is specific to families enrolled in the CSHCN Services Program. However, since the eligibility requirements are similar for case management services and for the CSHCN Services Program, it's possible to make generalized educated assumptions based on the types of diagnoses among CSHCN receiving case management services. Figure 35 presents the diagnosis categories among CSHCN. These diagnosis categories were organized by the TXICFW team with the full data of diagnoses among CSHCN Services Program clients for FY20 in Appendix D.

FIGURE 35. CSHCN DIAGNOSES CATEGORIES AMONG CSHCN SERVICES PROGRAM CLIENTS, FY20



Data Source: HHSC CSHCN Services Program Data. N=1,559

Less than 1% of the CSHCN Services Program clients had the following diagnoses, which are not represented in the above graphic: skin/dermatological disorders, reproductive disorders, liver disorders, and bladder/urinary disorders.

For FY20, the top diagnoses experienced by CSHCN Services Program clients are described in Figure 36.

FIGURE 36. TOP CSHCN DIAGNOSES AMONG CSHCN SERVICES PROGRAM CLIENTS, FY20



Data Source: HHSC CSHCN Services Program Data. N=1,559.

Diagnoses that were prevalent in less than 1% of CSHCN Services Program client data are omitted from the graphic above.

For FY20, the top five diagnosis categories among CSHCN Services Program clients were musculoskeletal disorders (18%, N=281), neurological disorders (17%, N=272), endocrine disorder (12%, N=185), respiratory disorders (10%, N=159), and

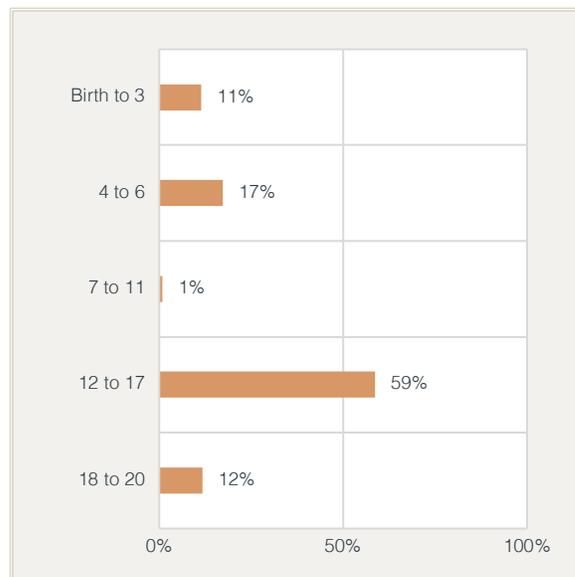
cancer/neoplasms (7%, N=113). When examining the number of clients by each specific diagnosis, the top five diagnoses experienced by CSHCN Services Program clients were seizure disorders (10%, N=163), cerebral palsy (10%, N=159), endocrine disorders (8%, N=127), malignant cancers (6%, N=101), and respiratory diseases (5%, N=82).

The top five diagnoses among CSHCN Services Program clients differs from the top five conditions collected from National Survey (NS-CSHCN), since the CSHCN Services Programs requires the CSHCN must have a physical diagnosis, while the NS-CSHCN data had a broader scope of conditions, including behavioral and mental health diagnoses in addition to physical conditions. For reference, the top five diagnoses among Texas respondents of the 2009/2010 NS-CSHCN survey were allergies (57%, N=479), asthma (37%, N=311), ADD/ADHD (29%, N=254), developmental delay/learning delay (17%, N=132), and anxiety (17%, N=134). Note: See Figure 4 for full list of conditions collected from the NS-CSHCN survey.

Age of CSHCN Served

Among CSHCN contractors providing case management services, the majority of CSHCN clients served were between the ages of 12 and 17 years old. DSHS regional data on CSHCN client ages was not provided to TXICFW. Figure 37 describes the distribution of age ranges among CSHCN case management clients served by CSHCN contractors.

FIGURE 37. AGE RANGES OF CSHCN CLIENTS SERVED CASE MANAGEMENT CSHCN CONTRACTORS, FY20

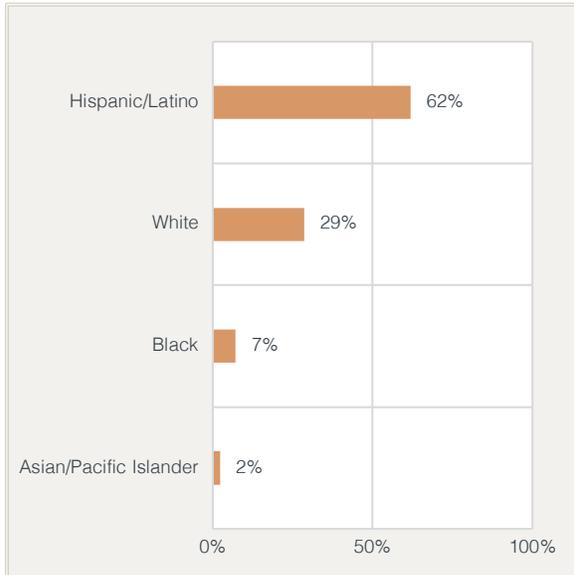


Data Source: DSHS Contractor Quarterly Reports FY20. N=1,001. Data does not show the 1 client who was 21 years old or older. Clients 21 or older must have cystic fibrosis to receive case management services.

Race/Ethnicity of CSHCN

Data on race and ethnicity of CSHCN clients was only provided by CSHCN contractors. CSHCN Services Program data collected by HHSC did not collect race/ethnicity data on clients, and TXICFW did not receive race/ethnicity data from the DSHS regional database (TWICES). Figure 38 shows the race/ethnicity distribution among CSHCN case management contractors.

FIGURE 38. RACE/ETHNICITY AMONG CSHCN CLIENTS, SERVED BY CSHCN CASE MANAGEMENT CONTRACTORS, FY20



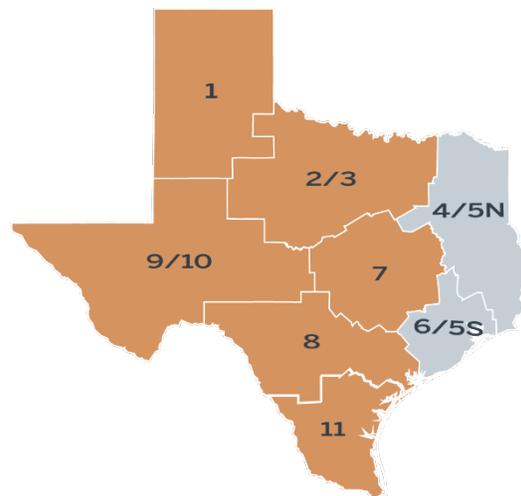
Data Source: DSHS Contractor Quarterly Reports FY20. N=961. Zero clients identified as Native American or Alaskan Native, therefore is not represented in the figure above. White is of non-Hispanic ethnicity.

Research has shown racial and ethnic disparities in family centered care for CSHCN, specifically with the amount of time providers spent providing care for CSHCN between Black and Latino CSHCN and white CSHCN.⁵¹ Even after adjusting for factors such as the child’s diagnosis, socioeconomic factors (e.g., poverty, household composition), and healthcare access (e.g., insurance type, having a personal physician), researchers confirmed that disparities persisted in the type of care received, which impacts short-term and long-term health and wellbeing outcomes for the family.⁵¹ It is important to consistently collect racial and ethnic demographic data among CSHCN and their families to better understand these disparities and identify solutions toward providing more equitable care.

Needs Assessment Outcomes: TXICFW Collected Data

This section will present outcome data among the participants involved in the research activities for the Needs Assessment conducted by TXICFW. The Needs Assessment aimed to recruit CSHCN staff and caregivers from each Texas region in order to gather a geographically representative sample for both interviews/focus groups and the online survey. Figure 39 below presents the participant sample for Needs Assessment activities.

FIGURE 39. NEEDS ASSESSMENT PARTICIPANTS



Interviews & Focus Groups

Interviews and focus groups were conducted via phone or video from July 13, 2020 to September 10, 2020.

Regions represented in orange:
Regions 1, 2/3, 7, 8, 9/10, 11

38 CSHCN staff participated in a total of **32** interviews & focus groups

28 were DSHS staff, **11** were CSHCN contractors

Job roles included eligibility specialists, case managers, health

educators, case management liaisons, administrative assistants, team leads, supervisors, managers, program coordinators, and directors

Staff representing all Texas regions participated in interviews/focus groups

11 caregivers of CSHCN participated in interviews

8 were completed in Spanish, 3 completed in English

Online Survey

The online survey collected data from October 20, 2020 – November 12, 2020.

All regions were represented in online surveys.

54 survey respondents were CSHCN staff

32 were DSHS staff

26 were CSHCN contractors and other organizations

41 survey respondents were caregivers of CSHCN

4 survey respondents were both CSHCN staff & caregivers of CSHCN

Each domain will also present COVID-19 impacts related to that domain, for example, COVID-19 impacts on providing referrals. While COVID-19 impacts are beyond the scope of this Needs Assessment, the effects of the pandemic fundamentally changed how families received services. This information was valuable to capture, considering the long-term effects that COVID-19 will have in our society and how case management is provided to a particularly vulnerable population of CSHCN. Appendix E summarizes the COVID-19 impacts presented throughout this report.

Identification, Screening, Assessment & Referral

The first section of findings relates to the first National Standard of CSHCN domain of *Identification, Screening, Assessment, and Referral*. Adapted to the scope of this project, this domain embodies the first crucial steps of the case management process.

- **Identifying** the families served through established eligibility criteria for case management, conducting outreach, and establishing provider relationships.
- **Screening** of CSHCN and their families for possible eligibility for programs, benefits, and other supports.
- **Assessment** of family needs and development of service plan.
- **Referrals** are provided as family needs are identified and/or change.

Needs Assessment Findings

This section discusses the findings from the Needs Assessment research activities organized into the five national standard domains of: Identification, Screening, Assessment, and Referral; Access to Care; Medical Home; Community-based Services and Supports; and Transition into Adulthood. While the National Standards of CSHCN defined these domains within the scope of the medical field, this report reframes these domains for the scope of this CSHCN Project, with case management at its core.

Identification: About CSHCN & Families Served

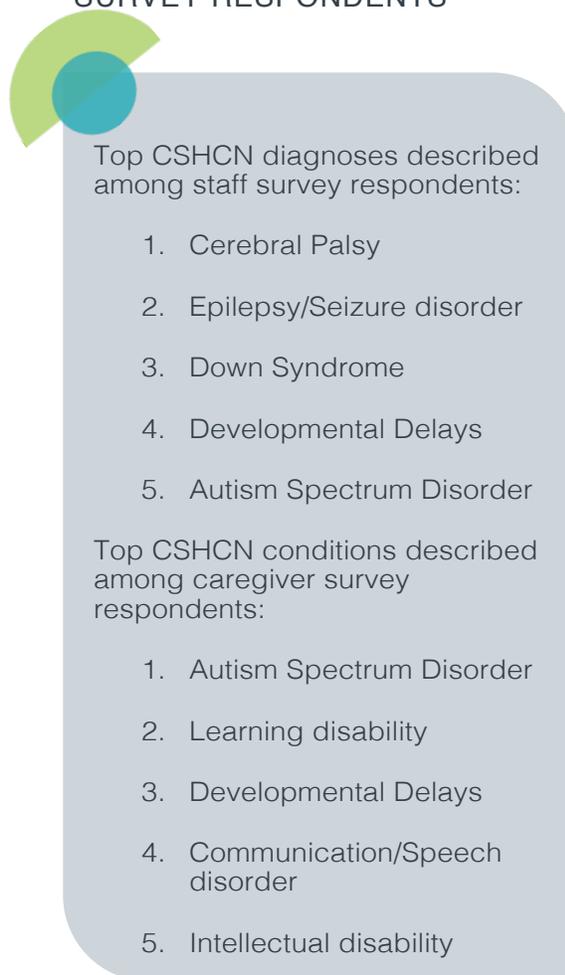
CSHCN Diagnoses

In order for CSHCN families to receive case management services and supports from DSHS, CSHCN must have a diagnosis that is biological, physical or cognitive and is expected to last one year. During interviews/focus groups with DSHS staff, many caregivers of CSHCN who

sought services from DSHS regional staff primarily wanted help applying for the CSHCN Services Program to gain health care coverage and necessary resources for their CSHCN. While DSHS regional case managers did not turn away case management from CSHCN families because of their diagnoses, the majority of DSHS staff interviewed mentioned that the CSHCN they served had at least one physical or biological diagnosis. Due to the lack of data collected on CSHCN diagnoses, TXICFW could not calculate the percentages of various diagnoses of children receiving case management.

From the online survey, staff and caregivers described a variety of diagnoses for their CSHCN. During interviews and focus groups, diagnoses most often mentioned were cystic fibrosis, autism, intellectual disability, and diagnoses affecting blood, bone, and muscles. DSHS staff often described that mental and behavioral health diagnoses were addressed only after a physical diagnosis was present, as they often served families who were in the CSHCN Services Program, which requires the CSHCN to have a primary physical diagnosis. In contrast, CSHCN contractors often discussed serving CSHCN who have either a physical or mental/behavioral diagnosis. However, each CSHCN contractor has their own eligibility criteria that was not collected by TXICFW.

FIGURE 40. CSHCN DIAGNOSES, SURVEY RESPONDENTS



*Data Source: 2020 CSHCN Online Survey. Staff N=57; Caregiver N=41
Note: Appendix D includes full data of CSHCN diagnoses from survey respondents.*

During interviews and focus groups, a majority of staff described a wide range in the severity of diagnoses, from those that are easily managed with prescription medication to medically complex children experiencing multiple diagnoses. While it is difficult to fully understand the severity among CSHCN served without client data capturing that information, the main takeaway from CSHCN staff interviewed was that the intensity of needs and services for families varies widely.

Undocumented Families

Through interviews and focus groups, majority of DSHS staff discussed that CSHCN services, especially the CSHCN Services Program, have been crucial resources for undocumented families since they often do not qualify for any other health coverage due to documentation requirements. Staff often discussed how beneficial the CSHCN Services Program is for families who would otherwise not have any health insurance or access to care for their CSHCN.

“Especially in the populations we serve, particularly with our children with special health care needs services programs, or the actual benefit programs. A good portion of those individuals on the program are folks who don’t have citizenship. Because one of the assets of the program is that it requires Texas residency but not US citizenship.”

– DSHS Staff

Demographics: Caregivers of CSHCN

Caregivers of CSHCN who participated in interviews and the online survey were asked to complete questions that collected demographic information about themselves and their household. Figure 41 presents demographic data among caregivers of CSHCN who participated in the Needs Assessment.

FIGURE 41. ABOUT CAREGIVERS, INTERVIEW PARTICIPANTS AND SURVEY RESPONDENTS



- **60%** of caregivers received CSHCN case management services in the past year
- **83%** Female; 6% Male
- **78%** between 35-54 years
- Race/Ethnicity: **53%** were Hispanic, **36%** White (N=42)
- Primary language: **72%** English, **28%** Spanish
- Relationship status: **78%** are married
- Education level: **25%** have Bachelor’s degree, **19%** have Master’s degree, **19%** have Associate’s degree,
- Caregivers’ household income in 2019 (N=36) ranged from less than \$20,000 (**22%**) \$20-34,999 (**24%**) \$35-49,000 (**17%**) \$50-74,000 (**20%**) and \$75,000 or more (**17%**)

Data Source: CSHCN Online Survey & 2020 CSHCN Pre-Interview Survey. Note: Relationship status and education level was only collected in the CSHCN Online Survey.

COVID-19 Impact: Financial Strain on Families

Due to the COVID-19 pandemic and public health social distancing

measures, staff expressed challenges in receiving referrals from their usual sources, such as pediatric offices and other community organizations. Prior to the COVID-19 pandemic, CSHCN staff described that they would typically drop off leaflets at pediatric offices and conduct outreach to organizations to share information about CSHCN services. Staff indicate a concern that families who would otherwise be eligible are not currently receiving CSHCN case management services due to the challenges of outreach during the pandemic.

Caregivers and CSHCN staff also discussed families experiencing financial strain due to job loss because of the pandemic. Some staff discussed the lack of childcare for their CSHCN, forcing caregivers to quit their job to stay at home to take care of their children. CSHCN are particularly vulnerable to COVID-19 due to their comorbidities, and while there is some childcare available, it may not be safe for CSHCN to attend.

"The reason why I wasn't working at this time is because will all the pandemic and everything going on with the COVID I had to leave work and I had to ask for the FMLAs, the emergency leave, the FFCRA, so I could be with my son because I don't have a daycare. There [are] no daycares around my area that can take care of my son. And, of course with the COVID going on nobody wanted to take care of my son because of course they don't want to be exposed to anyone... So, I don't receive any help. I don't receive any Medicaid. I don't have any help from the State or I have no help at all. So, when I met with her and she provided me all this, that was so helpful."

- Caregiver

Screening & Assessment

At DSHS regional offices, eligibility specialists play a key role in the first interaction and/or intake with new CSHCN families. During intake, eligibility specialists gather the necessary information from families to

identify which programs/benefits they may qualify for and begin assisting families in any application processes. While the exact role of the DSHS eligibility specialists varies across regions, this role has been crucial in submitting applications and paperwork early in order for families to gain resources or healthcare coverage, particularly the CSHCN Services Program and Personal Care Services program. Personal Care Services is a Medicaid benefit program that "assists eligible clients who require assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) because of a physical, cognitive or behavioral limitation related to their disability, physical or mental illness, or chronic condition."⁵³

Since the waitlist for the CSHCN Services Program can be quite lengthy, it is beneficial for families to apply quickly without first having to wait for a comprehensive family needs assessment by their case manager.

CSHCN case management contractors have their own organizational processes for helping families assess their eligibility for various benefits and programs across different organizations and regions.

Both the online survey and interviews/focus groups with CSHCN staff gathered information on how case management is provided to CSHCN families. This section discusses findings on three core case management processes of: 1) case assignment, 2) conducting a family needs assessment, and 3) developing a service plan.

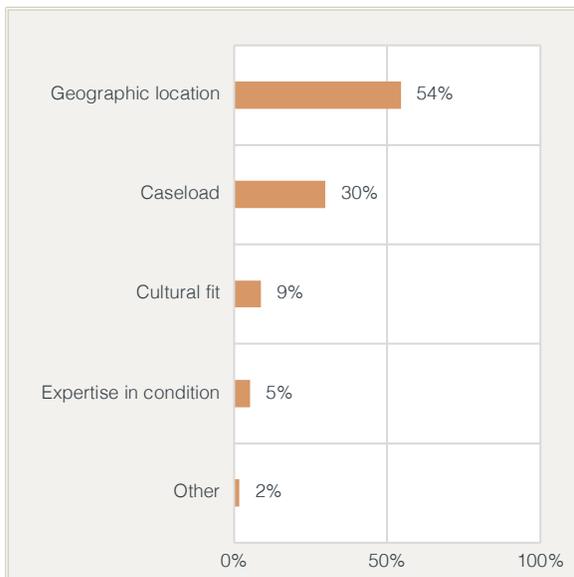
Case Assignment

Case assignment refers to the process through which a newly referred family is assigned to a case manager. Data from the interviews/focus groups and the online survey show that the case assignment process varies across DSHS regions and community organizations. From the online survey, 50% of CSHCN staff indicated that their organization has policies and protocols on case assignment, 15% of CSHCN staff indicated that they do not have case assignment policies or

protocols, and 35% were unsure. However, certain factors are typically considered in case assignment, indicated below:

- Geographic location of case manager and family (e.g., county, zip code)
- Case manager’s caseload and availability to take on a new family
- Preferred language among caregiver (e.g., bilingual case managers who speak Spanish would take cases whose caregiver speak Spanish only)
- Case manager’s expertise/knowledge about certain diagnoses

FIGURE 42. FACTORS CONSIDERED IN ASSIGNING CASES TO CASE MANAGER, STAFF SURVEY RESPONDENTS



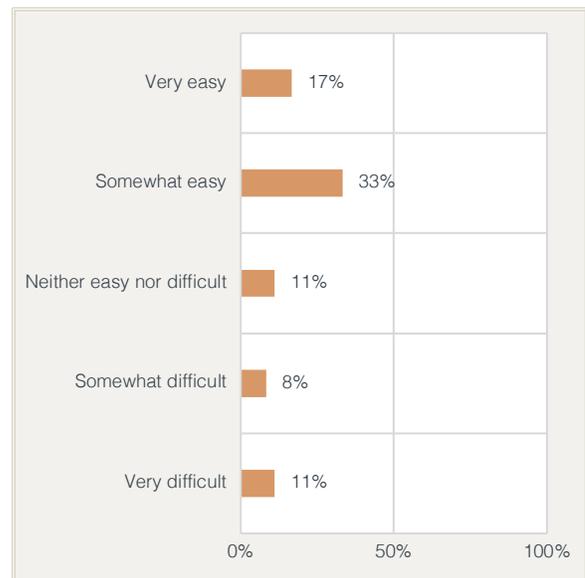
Data Source: CSHCN Online Survey. N=57. Cultural fit encompasses language spoken and cultural background of case manager and client.

In addition to these factors, some case managers discussed that cases were

assigned via a round robin process, meaning new cases were assigned to case managers based on a rotation. This data shows that the case assignment process varies across organizations and among DSHS regional offices.

The online survey asked caregivers how easy or difficult it was for them to get connected to a case manager. Figure 43 describes caregiver responses.

FIGURE 43. CAREGIVERS’ EXPERIENCE OF GETTING CONNECTED TO CASE MANAGER, CAREGIVER SURVEY RESPONDENTS



Data Source: CSHCN Online Survey. N=36

While nearly one-third of caregivers described getting connected to a case manager as “Somewhat easy,” this data shows that caregivers’ experiences vary widely.

During interviews, caregivers discussed getting connected to their CSHCN case manager through a variety of ways, including medical providers, staff from other social services programs (e.g., WIC), resource fairs, church, and from friends.

Family Needs Assessment

Among all case managers interviewed and surveyed, a family needs assessment is completed at the beginning of a new case, unless the family opts out. Some DSHS case managers discussed that certain families opted out of the family needs assessment if they only wanted assistance applying for the CSHCN Services Program, but did not want case management services.

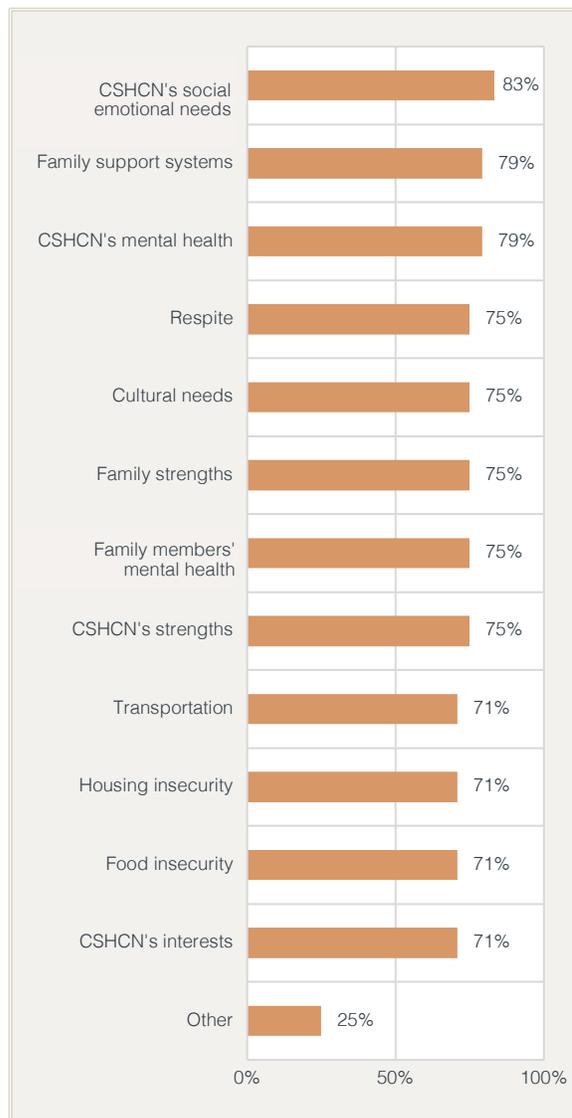
From the online survey responses, 85% of staff indicated that their organization completed a family needs assessment, and 96% of staff indicated that they use prescribed forms, tools, or guides to conduct a family needs assessment. Typically, the family needs assessment would be completed in person during a scheduled home visit. However, due to the COVID-19 pandemic, the family needs assessment is now completed primarily over the phone.

During interviews/focus groups, CSHCN staff opinions on the family needs assessment form and guides were mixed, with some discussing that form is effective and appropriate and others discussing that the family needs assessment forms are outdated and would benefit from a review and update. From the online survey, 96% of staff survey respondents said that the information collected in the family needs assessment is effective in helping families develop an individual service plan.

Similarly, the forms used by DSHS regional staff and CSHCN contractors vary, although they both collect information similar in scope. Some CSHCN contractors also discussed that they supplemented the DSHS family needs assessment form with their own forms and guides.

The online survey asked staff which topics they feel should be covered in conducting the family needs assessment. Figure 44 describes staff responses regarding which topics should be covered when conducting the family needs assessment.

FIGURE 44. TOPICS THAT SHOULD BE COVERED WHEN CONDUCTING A FAMILY NEEDS ASSESSMENT, STAFF SURVEY RESPONSES



Data Source: 2020 CSHCN Online Survey. N=24

Overall, the family needs assessment was comprehensive and gathered information not only from the CSHCN, but from the whole family unit. However, it would be beneficial to conduct a more in-depth review of all the family needs assessment forms, tools, and guides – both formal and informal to understand what areas are

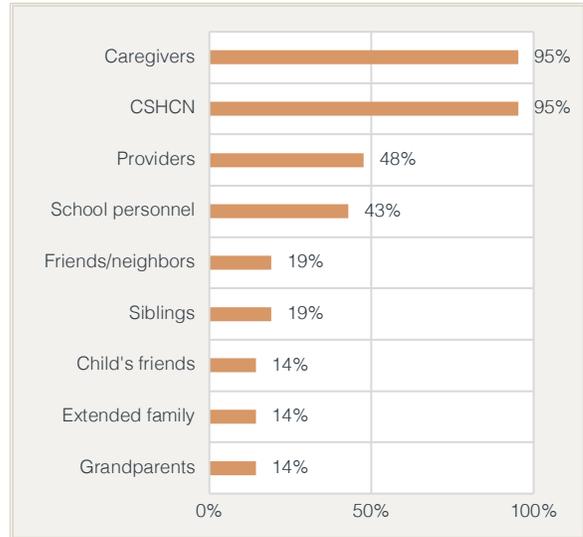
working well and what areas need improvement.

Individual Service Plan

The development of an individual service plan is typically a collaborative process where the case manager and family identify goals and outline actionable steps to meet their goals. The majority of CSHCN case management staff interviewed and 74% of staff surveyed indicate that an individual service plan is completed for families. Among all 22 CSHCN staff survey respondents who developed individual service plans, all of them used prescribed tools, forms or guides to complete the individual service plan.

The online survey also gathered opinions from staff about participants they feel should be actively involved in the development of the individual service plan. Particularly for CSHCN, there can be multiple service providers involved in a child’s daily life who are outside of the immediate family, most often health care professionals and school personnel. Figure 45 shows responses from CSHCN staff survey respondents on whom they would ideally like to include in the development of the individual service plan.

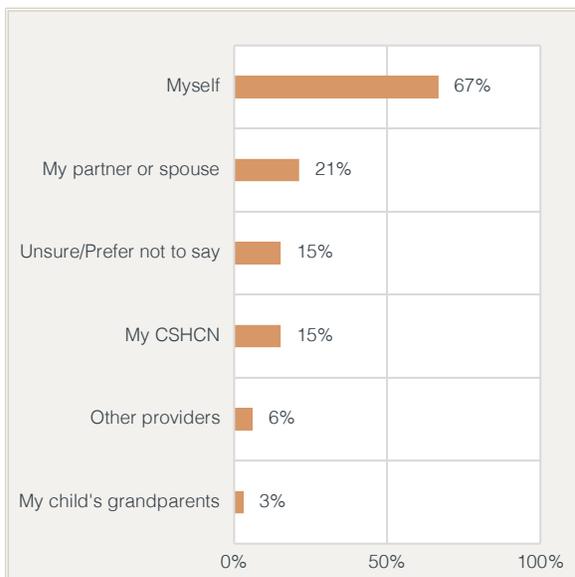
FIGURE 45. INDIVIDUALS WHO SHOULD BE INVOLVED IN THE DEVELOPMENT OF THE INDIVIDUAL SERVICE PLAN, STAFF SURVEY RESPONSES



Data Source: 2020 CSHCN Online Survey. N=21

The online survey also asked caregivers to indicate who typically interacts or has discussions with a case manager about family needs or concerns. Figure 46 describes who caregivers responded as being involved in discussions with their case manager about family needs and concerns.

FIGURE 46. INDIVIDUALS INVOLVED IN DISCUSSIONS WITH CASE MANAGER, CAREGIVER SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=33

This data shows that caregivers primarily involve their immediate family in discussions with their case manager. During interviews, caregivers discussed that case managers primarily contacted them (the primary caregiver) and if applicable, their partner.

“You have to let the families make that choice for themselves and recommend that they do their research on the providers. And that’s hard, because sometimes they don’t have access to the internet to do that. And there were times where you could say okay, if you go to the library, they have free computers and you can try to look at providers there. But right now, you can’t even do that.”

– DSHS Staff

In contrast, some staff discussed that most families had smartphones and were able to have meetings with case managers via Facetime or video conference. While in-person meetings were more ideal, they were able to switch to different virtual platforms to meet case managers and participate in telehealth appointments.

“We’ve been doing a lot of Zoom. We’ve been doing a lot of iPhone Facetime. And we’ve been doing a lot of phone calls and emails...Messenger on Facebook has been a good way for us to be able to see the children just like the iPhone has been a good way for us to see the children. [With] some families we still can’t do that. We’re actually just calling them and we’re talking to them over the phone.”

– CSHCN Contractor Staff

COVID-19 Impacts on Screening & Assessment

Due to COVID-19, all case management meetings for screening and assessment with families occurred virtually, either by phone or video. Prior to the pandemic, those meetings would typically occur in person. The technology challenges (e.g., video meetings, telehealth appointments) among families served were mixed, and access to technology was related to whether families lived in rural or urban communities. Staff discussed that families in rural areas typically did not have access to internet, lacked computers and devices, and lacked knowledge of how to use devices.

Referral

One of the primary resources that CSHCN staff provide for their families includes referrals to supportive services ranging from help with basic needs to referrals to specific therapies or resources (e.g., respite, Applied Behavior Analysis (ABA) Therapy, counseling). CSHCN staff discussed the strong symbiotic collaborations they had with other providers and healthcare clinics, wherein CSHCN staff were able to refer families to providers and providers were able to refer families to CSHCN staff for support.

Among DSHS staff, eligibility specialists discussed how they conduct outreach with different providers in their community, such as pediatric clinics and schools, to educate others about CSHCN case management through presentations, posting flyers, and building rapport with providers. Several staff discussed that relationships with providers established a two-way referral channel; a way for providers to refer families to CSHCN case management and a way for CSHCN case managers to connect families to specific providers.

Similarly, supervisors also discussed being involved in collaborations, such as CRCGs, to better connect with providers across the regions, which typically span many counties with varying ability of resources.

"I'm very involved in the CRCGs in the counties that I serve and all kinds of working groups in my area... [attending those meetings are] very helpful when I come across a family who is need of services. And so, some of the services that I'm aware of or that I utilize with my CSHCN families are Children's Special Needs Network, nonprofits that will offer things like respite, or diapers, or milk supply in the event that my client's not getting anything for three months from CSHCN."

– DSHS Staff

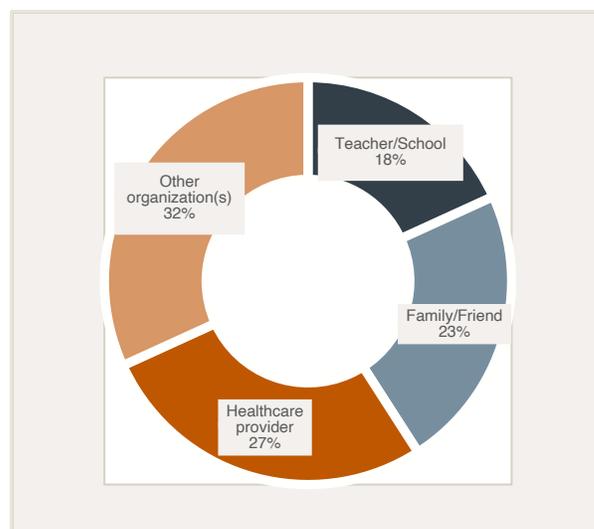
"I'm overly grateful that they're [case managers] there for us, making sure we don't lack anything and that we're not struggling with something. So, I'm very grateful for all of the work that they've done with us so far, and especially my daughter. Because the most helpful thing was that they fought for her to be accepted to be able to have her operation, which was the most expensive thing they charged me for." (Quote translated from Spanish)

– Caregiver

The online survey also asked caregivers how they were connected to case management services. Among

caregiver survey respondents, 47% received case management services from DSHS regional staff and 24% of caregivers received case management services from the DSHS contractors. Figure 47 presents findings from caregiver responses.

FIGURE 47. CAREGIVERS' CONNECTION TO ORGANIZATIONS, CAREGIVER SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=31

This data highlights the importance of the relationship and referral channels among community organizations.

COVID-19 Impact: Challenge in conducting outreach and gaining referrals

Staff discussed that the lack of in-person outreach and shifting priorities due to COVID-19 on healthcare clinics has slowed down the number of referrals they received from their established channels. While staff do continue to reach out to referral sources virtually, they report it is more difficult to make those lasting connections with providers, especially at schools, since COVID-19 has shifted those priorities.

"...before COVID, I loved going out into the community and letting them know

about my services. But now, the challenge is we're huge on social media. Internally, I've talked to many of my coworkers. But it's been a challenge trying to get referrals at this moment."

– CSHCN Contractor Staff

Access to Care

This section discusses findings from interviews/focus groups and online survey data on access to health care encompassing medical, behavioral, and therapeutic care. Especially for CSHCN who have higher healthcare needs than a typical child, access to health care is crucial for health and wellbeing. This section will specifically discuss the following topics related to access to care:

- Health insurance coverage for CSHCN and their caregivers
- Availability of providers to serve CSHCN
- Transportation challenges that impact accessing care
- Language barriers that impact access and quality of care

Access to Health Insurance

It is necessary for CSHCN to have health insurance in order to pay for any necessary medical, behavioral, and therapeutic care. There are several different types of public healthcare coverage programs available for CHSCN, such as Medicaid, children's health insurance program (CHIP), and the CSHCN Services Program. The eligibility and qualifications for families to receive these benefits is complex and beyond the scope of this project.

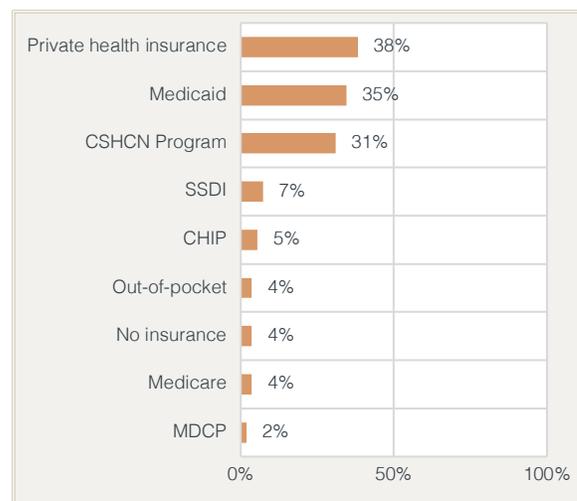
However, an important part of case management for CSHCN is ensuring families have applied to these health insurance benefit programs and then helping families navigate complex health care systems. While health insurance coverage does not always

equate to the actual receipt of needed care, it does serve as an indicator of accessing health care.

Health Insurance Coverage among CSHCN

Caregivers who participated in interviews/focus groups and the online survey were asked about health insurance they currently receive for their CSHCN. Figure 48 shows the types of health insurance among CSHCN, described by caregivers.

FIGURE 48. CSHCN'S HEALTH INSURANCE, CAREGIVER RESPONSES



Data Source: 2020 CSCHN Online Survey & Pre-Interview Data. N=55. Caregivers responses of "Prefer not to say" (4%) and "Unsure" (4%) were not included in the figure above. CHIP is Children's Health Insurance Program, SSDI is Social Security Disability Insurance, and MDCP is Medically Dependent Children's Program.

The data in the figure above shows that a larger percentage of CSHCN have private health insurance in addition to having public health care coverage for their CSHCN.

The online survey asked caregivers to estimate how much money they spent out-of-pocket over the past year related to their child's health care needs. Out-of-pocket costs included

insurance premiums, copayments, and other health care costs that were not covered by their CSHCN's health insurance. Figure 49 below shows the estimated out-of-pocket costs among caregiver survey respondents.

FIGURE 49. ESTIMATION OF OUT-OF-POCKET COSTS FOR CSHCN HEALTHCARE NEEDS, CAREGIVER SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=41. This survey question was from the 2014 Utah Survey of Children with Special Health Care Needs.

Despite the majority of CSHCN having at least some health coverage, this data shows that many families had to pay for additional expenses, some substantial, that were not covered by their CSHCN's health coverage. In another survey question, 41% of caregivers and 71% of staff indicated that their health insurance does not cover the services needed for their CSHCN, and 35% of caregivers and 51% of staff indicated that the high cost of services makes it difficult for families access the care they need.

"...So, I really feel like we're penalized in Texas for having a special-needs child. And, when I first moved here, they asked me, 'Well, aren't you on

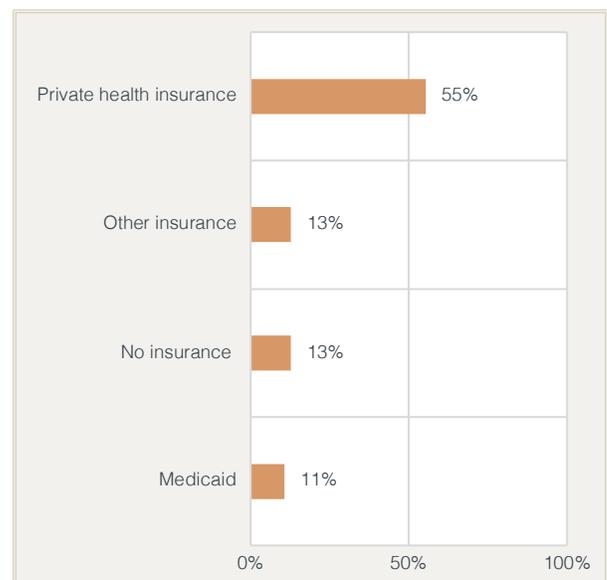
Medicaid?' And, I said, 'No, I'm the working poor.'"

– Caregiver

Health Insurance Coverage among Caregivers

In addition to learning about the CSHCN health insurance coverage, this study also aimed to capture whether caregivers were also able to access health care coverage. Research shows that caregivers who provide care for individuals with chronic or disabling conditions are themselves at risk of negative emotional, mental, and physical health outcomes due to the prolonged stress and strain of complex care management.⁵⁵ As case management for CSHCN families also focuses on the needs of the family, particularly the caregivers, it is valuable to gauge the ability for caregivers to access healthcare as well. Figure 50 describes health care coverage among caregivers who participated in this study.

FIGURE 50. CAREGIVERS HEALTH CARE COVERAGE, CAREGIVER PARTICIPANTS



Data Source: 2020 CSHCN Online Survey & Pre-Interview Data. N=47. Responses of "Prefer not to say" (4%)

and “Unsure” (2%) are not included in the figure.

Over half of the caregivers who participated in this study indicated that they have private health insurance, including employer-provided insurance and also insurance purchased independently by the caregiver.

One caregiver discussed the importance of checking in on the mental health and wellbeing of parents who have CSHCN:

“I think just update [check-in] on parents and see how they’re doing mentally too...I never dreamed this is what parents go through with the special needs and with the behaviors and just everything. So, look at how the family and how [the CSHCN] is doing and just make sure everything is going okay.”

– Caregiver

During interviews and focus groups, several CSHCN staff and caregivers discussed a specific challenge of locating CSHCN Services Program approved providers. They discussed that front desk staff and the providers themselves were uneducated about the CSHCN Services Program and refused to serve families or charged families out-of-pocket for visits, and then caregivers and case managers must resolve the situation. In some cases, this confusion would result in CSHCN not getting the care they were supposed to receive.

Caregivers and CSHCN case managers both suggested this confusion could be mitigated by simply having a CSHCN Services Program insurance card to present to healthcare providers, similar to Medicaid and other insurance programs. This card, in addition to providing a greater education about the CSHCN Services Program, could lead to more CSHCN-approved providers. For example, one caregiver described that this situation would occur routinely in getting needed care for her CSHCN:

“You simply come across the lady in reception who isn’t familiar with the [CSHCN Services Program], they don’t know it, and they tell you, ‘No. We don’t accept it.’...we come across that a lot, regarding that card. ‘We need your insurance card.’ And we present the form to them that the [CSHCN Services Program] sends us, and we say, ‘This is my card.’ And they say that it’s not, that we should’ve gotten a normal card, like an actual card. But I say, ‘No, we received this paper.’ And they say, ‘No, we need the card.’ And they don’t give us the service.”

– Caregiver

Lack of Qualified Providers

The primary challenge that was discussed by the majority of CSHCN staff was the lack of qualified health care providers that serve CSHCN. Three specific themes discussed about these challenges were:

1. Lack of healthcare providers in rural communities,
2. Lack of healthcare providers who serve patients with Medicaid and CSHCN Services Program, or changing qualifications for providers serving Medicaid and CSHCN Services Program patients, and
3. Infrastructure of health systems are de-incentivizing providers to serve patients with Medicaid and CSHCN services program.

Lack of Healthcare Providers in Rural Communities

During interviews/focus groups, the majority of CSHCN staff discussed the lack of healthcare providers in their communities. Staff emphasized that rural communities experience a lack of providers, particularly specialty health care providers, such as pediatric neurologists or psychologists. The lack of providers resulted in long waitlists for CSHCN, or families had to travel to different cities in order to receive care. From the online survey, 47% of

caregivers and 73% of staff indicated that long waitlists were a barrier for families to receive the services and supports they need.

“There’s not a lot, but there are certain doctors that are good with kids with special needs, but when it comes to specialist, everyone has to go either to Dallas, or Lubbock, or Houston because we don’t have specialists out here. We don’t have a developmental pediatrician out here either.”

– Contractor Staff

“There’s no limit on disabilities so there shouldn’t be any limit on how far it reaches out, you know?”

– Caregiver

Lack of Qualified Providers Changing Qualifications of Providers to Serve CSHCN with Public Health Insurance/Benefits

Another theme that emerged from interviews/focus groups was the lack of qualified providers that took public health insurance for CSHCN, such as Medicaid and CSHCN Services Program. While the type of health insurance varies among families served by CSHCN staff, a large portion of CSHCN received public health insurance/benefits, such as Medicaid and CSHCN Services Programs to cover health care costs. However, the range of health care providers who accept patients with public health care coverage is often limited, and systems are overwhelmed with long waitlists.

From the online survey, 28% of caregivers and 61% of staff indicated that there is a lack of qualified healthcare providers in their community. Additionally, staff discussed that the list of approved providers who accept public health insurance options was outdated, since providers would need to stay up-to-date on paperwork to be a qualified provider. Several staff discussed frustrations experienced by families

being referred to a qualified provider from the approved list, but would later discover that the provider no longer accepts their health insurance, and some families were billed.

“[We need] more providers that accept all insurances because it doesn’t help for me to give a referral, and they don’t take a specific insurance. And then they’re back to square one...Because even with Medicaid and you think, “Okay, well, they take Medicaid.” “Oh, but we don’t take that plan. We take this other plan.” And this other provider takes a different plan, and so, it’s such a hassle. The parent has to be either choosing between providers, and it’s not right.”

– Contractor Staff

“Well, I guess in Dallas and Houston and all those places, they have special-needs dentists. Well, they don’t have that [here]. So, a lot of the dentists don’t know how to deal with it. We are going to one that’s pretty good right now, [but] one dentist here, I felt like he wanted to put [my child] under [anesthesia] again just to get his teeth cleaned every six months. That’s so expensive and everything, we can’t afford that.”

– Caregiver

Healthcare Systems Disincentivizes Providers to Serve CSHCN Patients

During interviews/focus groups, CSHCN staff were asked what needed to be changed in order to improve access to care for CSHCN. Majority of staff discussed that their community needed more qualified providers and specialists that take public health insurance. A systems-level theme emerged that described how the health care system de-incentivizes health care providers from taking patients with public health insurance (e.g., Medicaid and CSHCN Services Program) because it requires more paperwork and offers lower reimbursement rates compared to private health insurers. While this

challenge speaks to the health system infrastructure more broadly, it does highlight the structural challenges that prevent from CSHCN families from accessing the care they need.

“Particularly on the CSHCN insurance program, there’s a very limited provider pool. That’s one of the challenges of this. Because there’s a fairly small number of children statewide that are on the program, and for a medical or dental provider to be a provider for CSHCN, they have to first be a Medicaid provider. And so it’s just there’s a lot more paperwork that providers have to complete. Their billing is complicated. It’s really common that they get bills rejected and not paid. So, families will get bills and they’re not supposed to ever get billed.”

– DSHS Staff

Transportation

Transportation was also discussed as a challenge for CSHCN families to access care, particularly in rural communities where families had to travel long distances for appointments. Additionally, staff discussed challenges with Medicaid transportation options that were sometimes limited and required extensive planning ahead of time.

“The challenge of transportation is always a big one because most of our cities don’t have bus systems or public transportation. They can only use the medical transportation when they’re going to doctor appointments, but there are many other things they do that they don’t have a way to get to or they don’t have as easy access to.”

- DSHS Staff

“...the state would offer the referrals or refer me and even help me make the appointments, but all of them were out of town. So, yeah, the state would offer it and show me what was offered and what [resources] were out there – what

kind of help – but most of it’s just out of town.”

– Caregiver

Among online survey respondents, 12% of caregivers indicated that transportation issues are a barrier preventing them from accessing care, and 32% of caregivers indicated that the location of services was inconvenient. In contrast, 67% of staff indicated that transportation was a barrier for families to access care and 61% of staff indicated that the location of services was inconvenient. This discrepancy of the transportation barriers may be due to COVID-19 and the shift of services being offered remotely instead of in-person.

During interviews and focus groups, other themes around transportation challenges emerged, including families having only one car and difficulty traveling long distances with their child due to circumstances related to their healthcare need. Among families, many CSHCN cannot stay home independently and families must secure childcare, which is expensive and challenging to secure on short notice. One caregiver highlighted this challenge with her child:

“...also disabled kids, you ain’t taking them for long hour trips...And it’s hard to just go there for everything. [My child] don’t like to leave. Once he gets home from school, he don’t want to go anywhere at all...He’s through.”

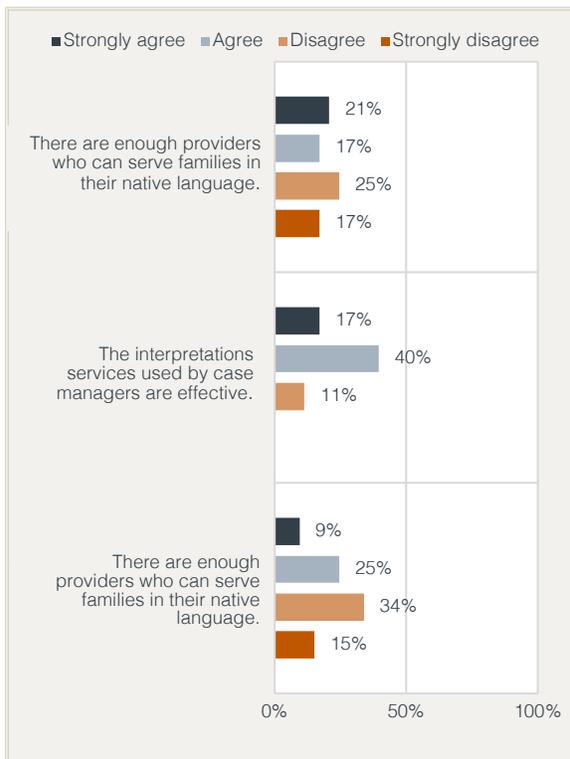
– Caregiver

Language Barriers

Language barriers greatly impact the ability of families to access care and resources for their CSHCN, particularly in navigating an already complex systems of care. In the online survey, staff respondents indicated that other than English, the most common languages spoken by CSHCN families are: Spanish (96%), Arabic (22%), Swahili (18%), and Vietnamese (14%).

During interviews and focus groups, staff discussed being able to effectively communicate with caregivers who spoke different language, most often Spanish, by having a bilingual case managers among DSHS staff or using a language line to help translate. Figure 51 describes staff survey responses on how much they agree or disagree with the following statements about translation services when providing case management to non-English speaking families.

FIGURE 51. TRANSLATION OF CASE MANAGEMENT SERVICES FOR NON-ENGLISH SPEAKING FAMILIES, STAFF ONLINE SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=53.

Overall, providing case management to non-English speaking families was feasible with the help of interpretation services. However, this data shows that there is still a need to have bilingual case managers that can serve families. During interviews and focus

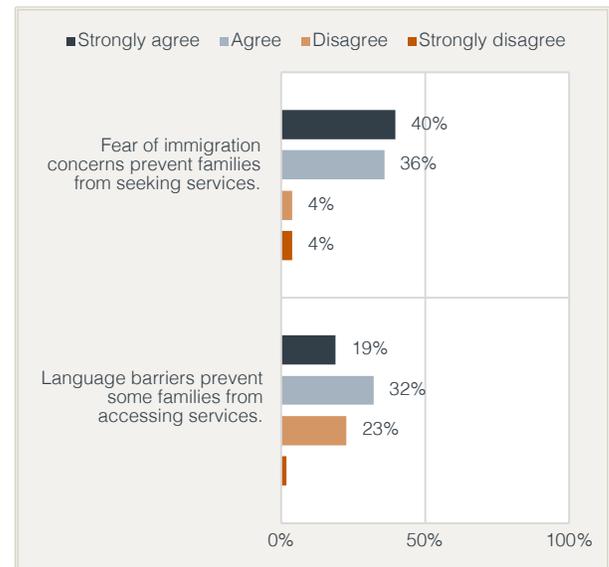
groups, staff indicated that the language line was helpful, but not ideal when trying to build rapport with families.

“For the families that they don’t speak English or Spanish, which are the two most common languages, even though we do have access to a language line, that is still quite difficult when they speak other languages. Because when you use a language line, you can’t guarantee that the interpreter is saying what you’re saying or that they’re interpreting your intent. So, that affects your ability to build rapport with families as well.”

- DSHS Staff

When asked about the language and cultural barriers in accessing care outside of the case manager, the staff survey responses were mixed, as shown by Figure 52. This may be due to the differences in accessing care in urban and rural communities.

FIGURE 52. LANGUAGE & CULTURAL BARRIERS IN ACCESSING CARE, STAFF SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=53

The majority of staff online survey respondents in addition to staff interviewed discussed the challenges of accessing care due to language barriers and fear of immigration. One caregiver discussed her experience of being unable to enroll her child in a class for independent living skills:

"But since [my] child at that time could not speak English, they told me, 'All we have is [this class] in English, [teach your child] how to speak English.' So I no longer paid attention to that, I no longer focused on that." (Quote translated from Spanish)

– Caregiver

The online survey captured a mixed response among 10 Spanish-speaking caregivers about their experience in how often they received translated CSHCN forms and written materials. Thirty percent said materials were "Always" translated, 30% said materials were translated "Most of the time", 10% said materials were translated "About half of the time" and 10% said materials were translated "Some of the time." Although this is a small sample size of Spanish-speaking caregivers, it does indicate that there are differences in the availability of translated CSHCN forms and written materials across regions and organizations.

"One of the things I do have an issue with is when we do the family support services. Not all of the documents that we use are in Spanish. There is a great emphasis on most of our brochures are in English or in Spanish. And some of them are also in Vietnamese. But when we have a family support services application, the main portion of it is not in Spanish. And if we're explaining a program to families, we really should be able to hand them that information in their language."

– DSHS Staff

COVID-19 Impacts on Access to Care

From this study, two themes emerged indicating how COVID-19 impacted how families' access care: 1) Shift to electronic paperwork and allowing authorized signatures from case managers and 2) shift to telehealth visits.

ABILITY TO ELECTRONICALLY SUBMIT PAPERWORK/DOCUMENTATION FOR THE CSHCN SERVICES PROGRAM.

Many CSHCN staff from interviews/focus groups and the online survey discussed how both the shift in allowing case managers to be the authorized signatory for families and the shift in ability to accept electronic versions of documents has been beneficial for timely submission of paperwork, and it is less burdensome of families. Staff discussed that they hoped this change in paperwork submission would continue.

"So, COVID has been a bit of a blessing and a curse... Because before COVID, we needed a lot of the original copies, for instance, the application [and proofs of documents]... Since COVID has happened... it's a lot easier to get proofs from these clients and their families because we're able to accept electronically submitted applications and other proofs."

– DSHS Staff

SHIFT FROM IN-PERSON HEALTHCARE VISITS TO TELEHEALTH VISITS.

Caregivers and CSHCN staff discussed the shift from in-person health related visits to telehealth visits among families who had the technological capacity. Of the caregivers we spoke to, the shift towards telehealth visits was not preferred compared to in-person visits, particularly for physical health checks.

However, there were a few examples from staff discussing how telehealth enables better care coordination among different providers by enabling the different providers to attend the same virtual visit.

“And we’ve been working on federal contracts to help do some telemedicine... And in some of the rural hospitals, I’ve seen a psychologist or mental health specialist from Dallas working with the family in [rural Texas city]. And they do it via telemedicine. So, yes, that is a silver lining [of COVID]...Some of my families have commented to me as well that they like having these tele[health] visits with their family.”

– CHSCN Contractor

One caregiver discussed that they preferred having in-person healthcare visits with their CSHCN’s doctor and explained how telehealth visits were more difficult to communicate with the doctor.

“Well, the only difficult thing has been because it is a video call. It is not the same as when you go in-person, because the doctor checks him, weighs him. And it is better...And it is difficult because [my child] does not speak. It is difficult to help the doctor, to tell her, ‘You know what, this and that happened.’” (Quote translated from Spanish)

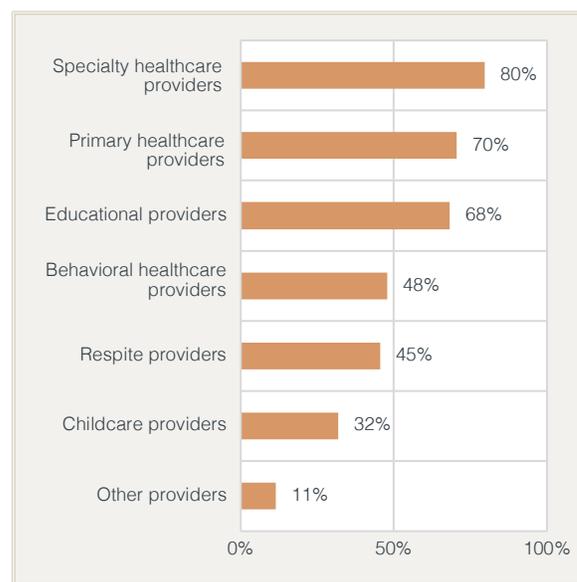
– Caregiver

Medical Home & Care Coordination

Care coordination through an established medical home is one of the core best practices identified by the National Standards for CSHCN. While the National Standards define medical home and care coordination within the healthcare field, reframing the scope of care coordination for CSHCN case management may also include other providers, such as school personnel. The online survey gathered information on medical home and care

coordination from CSHCN staff and caregivers. From the online survey, 85% (N=52) of CSHCN staff indicated that CSHCN have multiple providers and 67% of staff indicated that families have an established medical home. Staff were asked which providers they typically coordinated with, presented in Figure 53 below.

FIGURE 53. PROVIDERS CSHCN STAFF COORDINATE WITH, STAFF SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=44. Responses of “Unsure/Prefer not to say” (5%) were not included in the figure above.

Majority of CSHCN staff indicated that they coordinated with health care providers and educational providers. Other providers included those who supply durable medical equipment, Child Protective Services (CPS), and organizations that provide free resources and support groups to families. During interviews and focus groups, staff discussed that there was collaboration with other providers, but routine care coordination was not a major theme and required a lot of effort on the case manager.

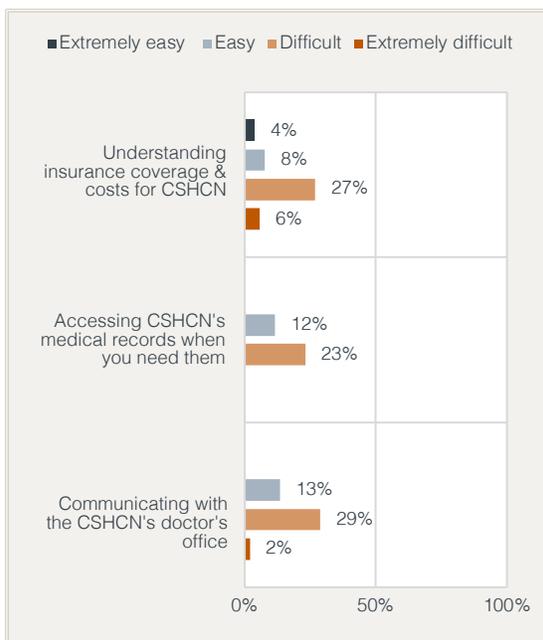
“... when [care coordination] happens, I mean it’s wonderful. But typically, it does fall – for my cases – on me to

have that coordination, to create that coordination. So, yes, but it is possible. It takes effort on our part to get that going. Typically, the client comes in without any other supports. And then it is up to us to then create that support system, to bring in, 'Okay is there a specialist? Is there a therapist that will provide mental health support?' you know bring all that in for this child and their family."

– DSHS Case Manager

The online survey also asked questions about the level or ease or difficulty with which staff can communicate with medical providers and obtain information from healthcare providers. The answer options ranged from “Extremely difficult,” “Difficult,” “Neither difficult nor easy,” “Easy,” “Extremely easy,” and to “Unsure/Prefer not to say.” Figure 54 below present the responses from CSHCN staff.

FIGURE 54. COORDINATION EXPERIENCE WITH HEALTHCARE PROVIDERS, STAFF SURVEY RESPONSES

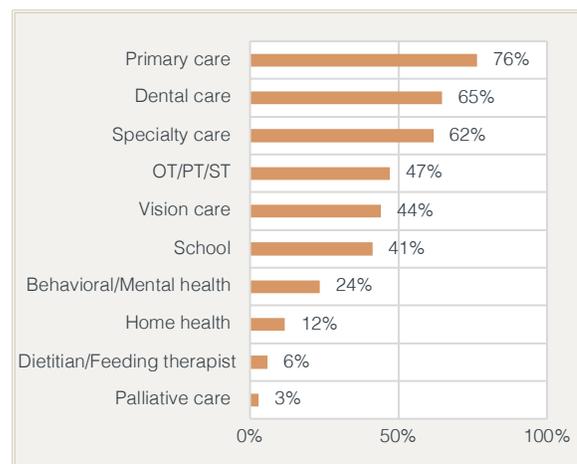


Data Source: 2020 CSHCN Online Survey. N=52. Responses that had less than 10% do not have a data label in the above figure.

Over one-third of staff indicated that it was neither difficult nor easy for each of these questions related to coordination with the CSHCN’s health care provider. However, a large percentage of staff indicated that communication and collaboration with healthcare providers was more difficult.

The online survey also asked caregivers about the type of providers who are currently providing care to their CSHCN. Figure 55 presents these responses.

FIGURE 55. CURRENT PROVIDERS FOR CSHCN, CAREGIVER SURVEY RESPONSES



Data Source: 2020 CSHCN Online Survey. N=34. OT/PT/ST refers to Occupational Therapy/Physical Therapy/Speech Therapy providers.

Caregiver survey respondents and interviewees primarily discussed that their CSHCN had multiple healthcare providers. Among caregiver survey respondents, 47% indicated that these CSHCN providers are aware of each other and the services that they provide.

From interviews with caregivers, it was not evident that caregivers had a medical home model, where all providers were routinely collaborating as a team to provide services. Caregivers often discussed that their case manager was available to help

support the caregiver in discussions with other providers. However, it was not evident that their case managers were in routine communication with other providers.

“...the social worker also told me, ‘No. If you need us to go with you and talk about those things with the nurse and the school principal, just tell us the date and time, and we’ll be there to back you up.’” (Quote translated from Spanish)

– Caregiver

COVID-19 Impacts on Care Coordination

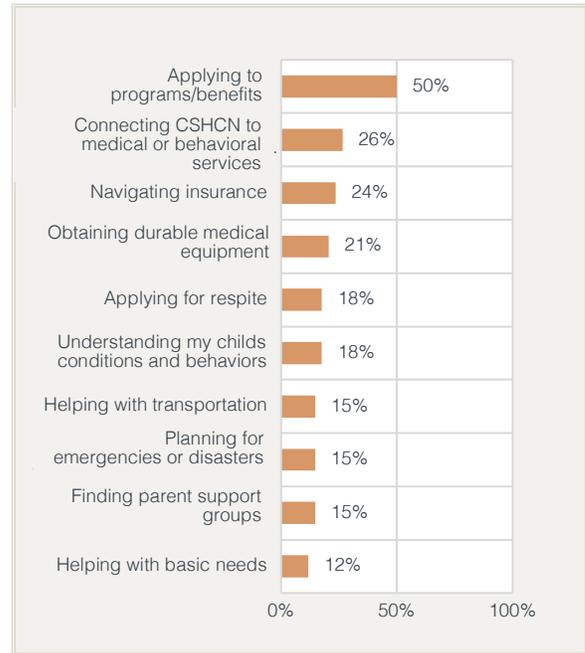
From the data collected for this Needs Assessment, there were no major COVID-19 impacts observed in regards to CSHCN medical home or care coordination.

Community-based Services & Supports

Community-based services and supports ranged from basic needs support (e.g., food assistance, rent assistance), to specific needs, such as connecting families to legal assistance. Supportive needs, such as to parent support groups or CSHCN play groups, were also an important resource to help build a sense of community among CSHCN families that can often be isolated in their communities.

Figure 56 presents the top ten types of community-based services and supports that caregivers indicated receiving from their case manager.

FIGURE 56. TYPES OF SERVICES AND SUPPORTS RECEIVED, CAREGIVER SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=34

During interviews, many caregivers discussed how their case managers helped their family with resources for basic needs and how grateful they were, especially among families whose jobs and income were affected by COVID 19.

“...they’ve helped me right now with the rent, now that I’m out of work, and my husband is also struggling. They gave me money for groceries. [My case manager] called me to tell me that they’re going to help me with school supplies, now that the kids are going to enter school.” (Quote translated from Spanish)

– Caregiver

During interviews, caregivers also discussed how there is always a need for services and supports to improve wellbeing. Many caregivers expressed how they would like more opportunities for socialization and integration of their

CSHCN in the community. Respite and childcare were the two types of services and supports that were most needed among caregivers for CSHCN, and they were also the most challenging for families to receive.

Challenges: Respite

Staff and caregivers discussed the disparity between the significant need of respite services for CSHCN and the lack of access to or availability of respite services in their communities. Two themes emerged when staff discussed challenges faced by families when trying to access respite services: 1) lack of respite providers who are able to care for CSHCN, and 2) burdensome paperwork to receive respite services through benefits/insurance program.

“Well, I don’t think there’s ever enough respite-type services ... just somebody that can give them a break once in a while. And the CSHCN program has respite. Really, it ends up being about 30 hours a month. And that’s helpful but there’s a whole complicated process to get that approved. And often, it doesn’t get approved.”

– DSHS Staff

During interviews, many caregivers discussed the administrative challenges in getting respite. For some caregivers, respite services were covered by their CSHCN’s healthcare/benefits program, but the hours were limited, there were certain restrictions, and the caregiver was responsible for finding a respite provider and coordinating between the respite provider and the healthcare program. Some have discussed that the disconnect between the respite provider and program benefit has resulted in missed payments that ultimately fall on to the caregiver to resolve. One caregiver shared her experience about the restrictive program requirements that resulted in her respite provider not being covered because the provider had recently moved.

“But what I never imagined, that [getting respite] was going to be so complicated... the truth is that this has been a headache... Now the problem is that the respite person [provider] has moved, and the only thing the respite people can tell me is that I have to do everything again. It’s like starting over again... And we are upset, both the [respite] person and me. Because this person comes to do his job. And of course, because he knows me, and because I trust him, I decided that he was the right person to take care of [my child].” (Quote translated from Spanish)

– Caregiver

Challenges: Burdensome Paperwork

Staff also discussed burdensome paperwork requirements in order to obtain durable medical equipment or when requesting vehicle modifications. While the services are provided by community contractors, paperwork must be submitted to insurance/benefits program (e.g., CSHCN Services Program, Medicaid) and approved in order for the program to cover the costs.

“The most difficult I could say would be definitely the paperwork. There’s a lot of paperwork that goes with these services. A family of mine was receiving respite care through the CSHCN program, and it literally almost took me a year of paperwork, of back and forth paperwork to get this service for a family... Every year, we have the same issues over and over again, and it has to do with the paperwork, and prior authorization, and a T not being crossed and I not being dotted. And it causes months of not getting supplies.”

– DSHS Staff

One caregiver echoed this same frustration with the challenges in trying to acquire safety equipment for her CSHCN:

"We looked at [getting] a seat harness and it's like those people don't get back in touch with me and that's something else where the school failed. The school can't do everything you know, but [my child's] teacher, she tries to do all she can too and she's tried to get me the car seat and find the funding or people that'll get it for you because it's like \$135.00 just for a little seatbelt strap or something...Anyway, needless to say, the whole year's passed and we never seen one."

– Caregiver

Spotlight on Services & Supports Provided by Contractors

The CSHCN community-based contractors offer a variety of supportive services for CSHCN. Below are some highlights of some of the services provided to CSHCN families.

Sibling Support Groups

SHARE provides sibling support opportunities specifically for siblings of CSHCN, in order to create space for siblings to bond and feel supported as children and their caregiving role that may last a lifetime. SHARE hosts Sibshops which is part of The Sibling Support Project, that is the first national program that support siblings of individuals with special health, developmental, and mental health concerns.⁵⁵ Sibshops are centered around the experience of siblings with a focus on building relationships with each other and having fun together. Some opportunities that are provided during Sibshops include opportunities for:

- Siblings of CSHCN to meet other CSHCN siblings,
- Siblings to have fun together by engaging in various activities and playing games, and
- Space to talk about the positives and challenges of being a sibling.⁵⁵

Socialization & Activities for CSHCN

Staff discussed various socialization and engagement activities for CSHCN that occurred before COVID 19. Some of these activities were specialized for CSHCN with certain diagnoses, while others were more broad, open to any CSHCN.

For example, during interviews and focus groups, one CSHCN staff discussed an equestrian event for CSHCN with ADHD, which provided an opportunity for children to learn more about their diagnosis, connect with others, and connect with horses. Another CSHCN staff member discussed opportunities in their communities where they would rent out movie theaters and invite CHSCN and their families to attend. This helped create a safe space for CSHCN to participate in a fun community activity without fear of repercussions of any disturbances by CSHCNs.

Parent support groups

Multiple contractors discussed hosting parent support groups and connecting CSHCN families together during family-friendly and holiday events. Many staff discussed how lonely and isolating the experiences of CSHCN families can sometimes feel. Staff discussed how opportunities for CSHCN parents to meet each other were impactful and resulted in lasting relationships of families. In some instances, families were able to help each other with child care while the other parent would run errands or take time for themselves. It is apparent that these parent support groups provide invaluable support and lasting relationships.

Among CSHCN Contractors, the following organizations host parent support groups for CSHCN caregivers:

- Any Baby Can – Austin
- Any Baby Can – San Antonio
- Open Arms (Bryan's House)

- Paso del Norte Children's Development Center
- Texas Parent to Parent
- SHARE
- Angelina Counties and Cities Health Department (starting in Q1 FY21)
- West Texas Rehab Center

During interviews, some caregivers were not aware of these support groups, especially among Spanish-speaking families. However, they were enthusiastic about the possibility of a parent support group in order to feel connected to other CSHCN families.

"...[that would be] good [to have a parent support group], that there could be a contact between parents who speak Spanish. Because I also speak in English, but I prefer Spanish for all these things because I understand it better, because they are topics that I think should be in my language. So it's good that there are parents who speak Spanish, and we could have as the contact." (Quote translated from Spanish)

– Caregiver

COVID-19 Impacts: Community-based services and supports

Lack of respite care but ability for some families to gain in-home respite.

Due to COVID-19, many contracting organizations that have respite services for families are unable to provide respite. However, some CSHCN organizations have mentioned that some families are able to get in-home respite care. While any support is helpful, one contractor staff discussed the high stress levels due to all family members being at home all day.

"...And then some families would also receive financial support. So, they would find their own respite provider to do in-home respite for them. So, I think that that has completely stopped because of COVID, and now, then on top of that, the kids are all day at home with no opportunities to get out of the house, to go to school, or to go a summer camp, or an after-school program. So, I think the stress levels for a lot of the families are really high. So, they're getting no break."

– CSHCN Contractor staff

Lack of childcare for CSHCN.

Staff and caregivers discussed the lack of childcare options due to COVID-19, particularly for CSHCN. Since CSHCN are at a greater risk for COVID-19, families and childcare agencies alike were not accepting CSHCN at childcare agencies. Some caregivers also discussed the challenges of finding adequate childcare during COVID, especially with schools being closed during the beginning of the pandemic.

One caregiver highlighted the paradoxical impacts that come with the lack of childcare, challenges in securing a job, and the lack of school during to COVID:

"I'm not working now due to childcare. They didn't have nobody in this town that sees kids. They would only see school kids and it was only afterschool hours and [my child is] in school, of course... [my child] didn't go to school after spring break because of COVID and then they never went back... They wouldn't offer me the childcare unless I was already working, and I wasn't working before because I had quit my job [due to the lack of childcare]... So, you got to be working to get the childcare services or you don't get them."

– Caregiver

Access to COVID-19 grants and financial assistance to families.

Some staff discussed that COVID-19 has allowed for their organization to receive grants to provide basic needs assistance and/or emergency financial assistance for families. Staff were also appreciative of flexibility in contract requirements to provide emergency funds for families.

“...recently with the pandemic, we received some funding to assist families with basic needs. So, we have been able to assist families with mortgage, rent payment, utility assistance. Because we are dealing with families that have either lost their job, their hours have been cut. They’ve been suspended for two weeks or three just because of trying to limit the virus being spread...this is something that families were like, ‘I’ve been limiting my kids as to what they eat.’”

– CSHCN Contractor staff

Shift to virtual parent support groups has expanded its reach.

Staff and caregivers discussed that while they prefer in-person meetings with other parents, having virtual parent support groups via Zoom has allowed for more families to participate since travel is not required. One contractor discussed that during COVID-19, they started a Spanish-speaking Zoom parent group that has been very successful.

One caregiver described how conferences were typically far away and difficult to attend, but these opportunities are now available on Zoom.

“But I tell you that far away locations are very complex for us. We only have one car...I think that if it can be done right now that everyone is with Zoom and everything, if it can be done with Zoom, excellent.” (Quote translated from Spanish)

– Caregiver

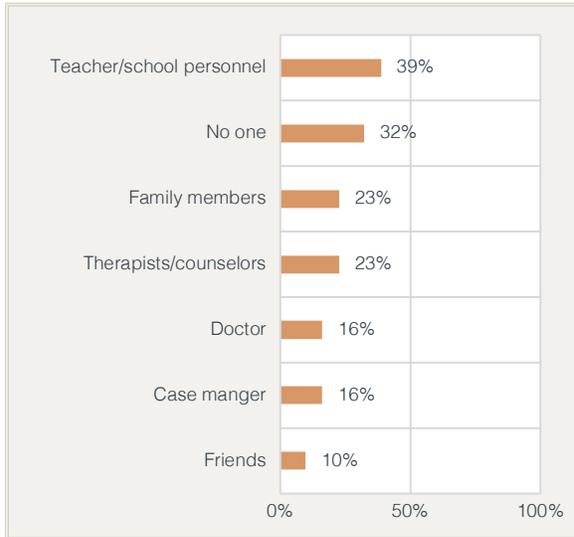
Transition Age Planning & Disaster Planning

As discussed in the literature review section of this report, transition age planning, also referred to as transition planning, is a crucial part of ensuring CSHCN are supported and prepared for independent living as an adult with special health care needs. The second part of this section will discuss disaster planning for CSHCN and their families. Helping families feel prepared during emergencies and disasters is a common case management practice, which also may require some additional activities and planning for CSHCN.

Transition Age Planning

The National Standards for CSHCN recommends that transition planning begin as early as 12 years old. From online surveys, 31% of staff discuss transition planning when the CSHCN is 11 to 12 years old. Of the 17 caregiver survey respondents, 71% indicated that they first discussed transition planning when their CSHCN was 10 years old or younger. Based on the data collected, CSHCN families served are starting transition planning at the recommended age for their CSHCN. The online survey also asked caregivers to indicate with whom transition planning is typically discussed. Figure 57 presents these findings from caregiver survey respondents.

FIGURE 57. PEOPLE WITH WHOM CAREGIVERS HAVE DISCUSSED TRANSITION PLANNING, CAREGIVER SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=31. Responses for Prefer not to say (10%) were not included in this figure. Teacher/school personnel, Therapists/counselors, and Doctor all refer to the CSHCN's providers.

From the online survey data, the CSHCN's teachers and school personnel were the largest group that discussed transition planning with caregivers. A key component in transition planning is helping the CSHCN and their families prepare for their CSHCN's transitions into new school environments, such as from elementary school to middle school. From interviews/focus groups, these transitions can be particularly challenging for CSHCN who thrive on consistency and structure in their daily lives.

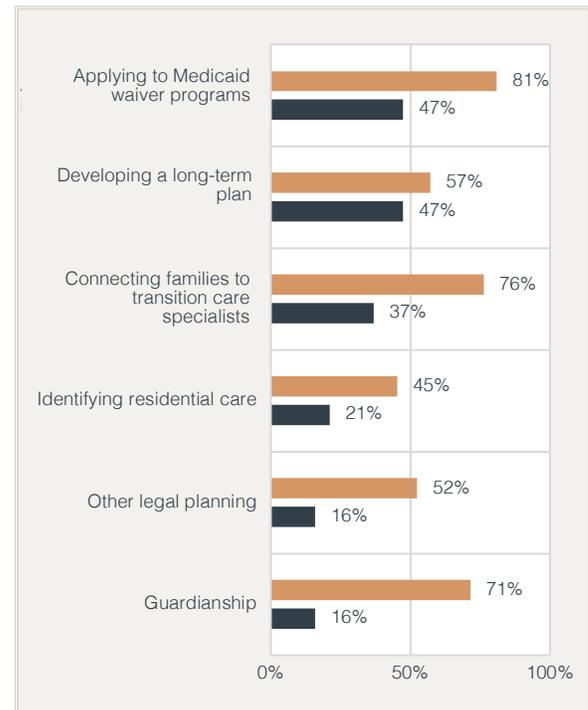
A portion of caregiver survey respondents also indicated that they have not discussed transition planning with anyone else and manage it on their own. Similar to themes observed throughout this report, caregivers of CSHCN often manage their child's needs on their own. This finding highlights that caregivers are in need

of greater support in transition planning.

Types of Transition Planning Activities

While the National Standards for CSHCN focus on transition planning within the healthcare sector, this section expands transition planning to include transition planning within the school system (e.g., elementary school to middle school), housing transition (e.g., independent living options), legal planning (e.g., guardianship), and other topics, such as sexual health and financial education. Figure 58 describes online survey responses from CSHCN staff and caregivers on the types of transition activities they have engaged in.

FIGURE 58. TRANSITION PLANNING ACTIVITIES, STAFF & CAREGIVER ONLINE SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. Staff N=42; Caregiver N=19

During interviews, many caregivers discussed that their case manager talked to them about transition care

planning. When asked about the type of transition plan activities they discussed with providers, most mentioned guardianship in the event of emergencies and ways to prepare their child for independent living.

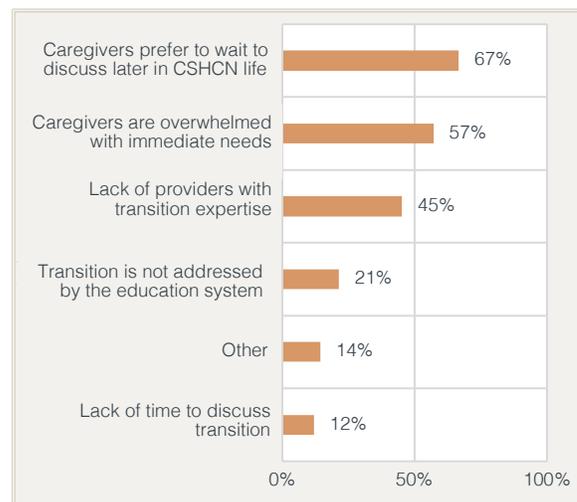
One caregiver described the types of transition planning activities for her CSHCN:

"...[The type of activities are about] helping to plan for my daughter's future... it's for her to go along setting goals, having that faith that she's going to be able to go on and have a career and be someone. So that she doesn't feel stuck because of what she has. And that's what I want the most, is for her to see beyond everything and see that no matter what we have, we can do it all. Because I've been sick, too, for many years, and I'm here, showing her that we can do it." (Quote translated from Spanish)

– Caregiver

The online survey and interviews/focus groups also captured the challenges in CSHCN transition planning. Figure 59 presents staff survey responses on challenges faced in transition planning.

FIGURE 59. TRANSITION PLANNING CHALLENGES, STAFF SURVEY RESPONDENTS



Data Source: 2020 CSHCN Online Survey. N=42. Responses for Prefer not to say (2%) and Unsure (5%) is omitted from the figure above.

During interviews/focus groups with staff and caregivers, several themes emerged about challenges in transition planning. These challenges span across multiple parties involved in the care for CSHCN, namely caregivers, CSHCN, healthcare providers, and school providers.

Caregivers are Overwhelmed with Addressing Immediate Needs

Many staff interviewed discussed that caregivers are overwhelmed and burdened with addressing their CSHCN's and family's immediate needs and that the notion of planning for their CSHCN's future is not adequately addressed. As discussed throughout this report, caregivers are tasked with managing a multitude of activities that are time consuming and physically, mentally, and emotionally draining. It is understandable that transition planning is a lower priority compared to meeting the CSHCN and family's immediate needs.

"I think their life is so day-to-day that they've learned that they can't plan for the future because things change every day. And so, I think that's part of it. Part of it, I think is just being exhausted and not having the energy to face another problem..."

– CSHCN Contractor Staff

One caregiver discussed that she was in the process of discussing transition planning, but that it is a difficult topic to discuss:

"Yes, we had discussed it. In fact, we're still in the process, we haven't finished it yet. Because in one of those transitions as well, or paperwork, on in those plans, it said that we'd also have to think about if something were to happen to us, and also about who [my child] would stay with. But, well, it's a very difficult topic." (Quote translated from Spanish)

– Caregiver

Lack of Providers Who are Equipped to Serve Adults with Special Health Care Needs

Nearly all interviews/focus groups with staff discussed the sudden absence of providers and services once CSHCN turn 18 years old, particularly medical care for children with special health care needs. Staff discussed situations where caregivers experience such an abrupt end of support and resources that had otherwise been so consistent in the child's life up to age 18.

"The resources really drop off – not completely but almost completely, down to just a few agencies that work with adults with special needs. And that's really difficult for parents to accept because if they started with ECI and then they got case management and they've got the schools and they have all these supports, and then all of a sudden, their child is 18 and there's nothing."

– DSHS Staff

Lack of Coordination of Care During Transition

Another challenge discussed in transition planning is the lack of coordination among different providers, particularly among pediatric healthcare providers to adult healthcare providers.

"...it's a coordination of care issue as well, because it seems like the pediatric system is much better than the adult system. It seems like transitioning to adult care, even under the best of circumstances, is still challenging when you're trying to link with new specialists and things like that. And depending on the physician they're working with in the office, some of them are better at that than others at trying to point them in the right direction. And so, I still think it's a pretty disjointed system all around and frankly, I think we probably could be doing it better in some ways when it is feasible."

– DSHS Staff

Improve Transition Education in the Community

Staff also discussed the need for more education in the community about transition planning, particularly in schools and other organization that serve CSHCN.

"...there should be more education on transition. There should be more education within the schools... There needs to be more education for the parents, for the teachers, for support, for the families that support."

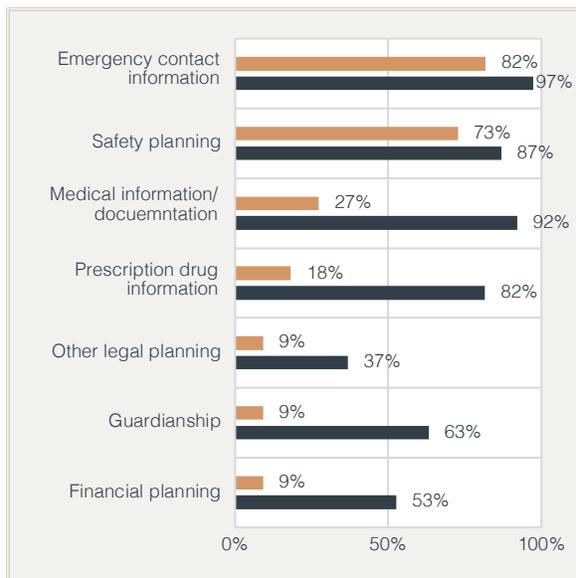
– Contractor Staff

Several staff discussed opportunities to improve transition care planning by providing more training and guidance. Some staff discussed that they attended a transition age planning conference and implemented strategies and tools to guide discussions with families on transition.

Disaster Planning

During interviews and focus groups, staff discussed that disaster planning was an established part of case management. From the online survey, 75% of staff discussed disaster planning with families and 53% of caregivers indicated that their case manager discussed disaster planning with them. During interviews/focus groups, case managers often discussed providing a packet of information to families, including documents for them to complete indicating important emergency contacts and medications for the CSHCN. Figure 60 describes the disaster planning topics covered by staff and caregiver survey respondents.

FIGURE 60. DISASTER PLANNING TOPICS DISCUSSED, STAFF & CAREGIVER SURVEY RESPONDENTS



Data Source: 2020 CSHCN Survey. Caregiver N=11; Staff N=38

Overall, staff were equipped to discuss documentation and importance of gathering contact information for disaster planning. This data suggests that there may be a disconnect of staff activities and caregiver experiences in more involved planning activities of

guardianship, other legal planning and financial planning with families. However, it is not known if caregivers who completed this question received disaster planning from staff who completed these responses.

Similarly, caregivers described that their case manager helped them plan for emergencies by providing them with a disaster planning packet that had emergency contact information and a helping plan for guardianship as some examples.

COVID-19 Impacts: Transition & Disaster Planning

There were no major themes observed specific to COVID-19 impacts to transition planning. Rather, they were similar to COVID-19 impacts discussed earlier in challenges to accessing services and supports for families. For disaster planning, the experience of going through a pandemic has encouraged some staff to include pandemic preparedness in future disaster planning policies and protocols.

Limitations

Convenience Sample & Small Sample Size

Limitations in the research methods exist and should be considered when examining the findings presented in this report. A convenience sample was gathered and participants were not chosen at random for both interview/focus group participants and survey participants. Therefore, these findings cannot be generalized to the entire Texas CSHCN population or CSHCN staff.

Both the online surveys and interviews/focus groups were voluntary; those who completed the surveys and participated the interviews/focus groups could potentially be unique from those that did not participate. Additionally, not all participants completed every question in the interview or survey. The sample sizes were small and may not be

representative of the larger Texas CSHCN providers. Caution should also be taken when interpreting results.

While the Needs Assessment aimed to recruit a diverse sample of CSHCN staff and caregivers, the study sample was not able to appropriately reflect the diversity of CSHCN and their families in Texas. Specifically for interviews and focus groups, our sample did not include fathers who are primary caregivers, Black caregivers, Asian/Pacific Islander caregivers, along with other racial/ethnic minorities. The absence of these participants in our study may not capture the experiences of these families. However, due to time limitations for this project, we were unable to dedicate more time to recruitment for diverse populations.

Limited Administrative Data & Wording

The lack of comprehensive administrative data provided to TXICFW results in limited understanding of the scope of data being collected and progress towards outcomes. The administrative data that was provided may include data entry errors or reporting errors that may impact findings. For the Needs Assessment tools developed by TXICFW, the wording of questions could have impacted comprehension for some participants.

Recommendations

The following recommendations are to inform and guide the development of the CSHCN case management practice model. Some recommendations, particularly in regards to data collection, would require systems-level changes that are beyond the scope of this project but have implications on the efficacy of CSHCN case management, CSHCN access to services, and CSHCN client experience. These recommendations are based on the literature reviews of CSHCN and case management practice models, as well as the Needs Assessment of CSHCN case

management in Texas conducted by TXICFW.

1. Improve Data Collection

Currently, all providers are collecting different types of data, and many are unable to retrieve data after inputting data in their database. In order to effectively understand how services are being provided and progress toward outcomes, data needs to be collected consistently across all regions.

TXICFW Recommends:

- Collect data that directly relates to desired outcomes (e.g., improved care coordination, improved family wellbeing)
- Collect comprehensive demographics data to be able to observe disparities in CSHCN and work towards mitigating disparities, particularly among Black and Latino CSHCN populations.
- Ensure data is easily accessible in both entering data and retrieving data.

2. Expand eligibility of CSHCN case management programming to encompass mental/behavioral health

Currently, there are three different types of eligibility requirements for CSHCN in Texas. In accordance with the National Standards for CSHCN, eligibility requirements should align to improve equitable access to services for families across regions. While the CSHCN Services Program eligibility is determined by HHSC and theoretically should be separate from CSHCN case management, the vast majority of families receiving

CSHCN case management by DSHS regional staff have their child as a CSHCN Services Programs client or on the CSHCN Services Program waitlist. This suggests there is a coordination of these two entities, HHSC and DSHS Regional Offices, since the families eligible for CSHCN Services Program and the families being served by CSHCN programming by DSHS regional staff.

TXICFW Recommends:

Align eligibility requirements for providers using the CSHCN case management practice model to also serve CSHCN who have only a (or as a primary) mental/behavioral health diagnosis. Requiring that the CSHCN's primary diagnoses must be physical is not consistent with National Standards and best-practices research and leaves out a large population of CSHCN and their families who are in need of support.

3. Continue DSHS intake process & update the Family Needs Assessment

Among DSHS regional staff, the role of eligibility specialists conducting intake and collaborating with providers is working well and allows for families to have applications and paperwork to be submitted early prior to meeting with a case manager. Additionally, eligibility specialists were also valuable in building relationships and referral partnerships with providers that built a network of support providers for CSHCN and their families.

The family needs assessment process worked well for some case managers but was often supplemented by informal processes and guidance. Some case managers felt that the family needs assessment was outdated.

TXICFW Recommends:

Continue the intake role of eligibility specialists as they are crucial part of

the case management team, especially among CSHCN and their families who must navigate complex healthcare systems, documentation requirements, and community resource systems.

Re-assess the family needs assessment forms and guidance used by CSHCN providers to develop a best practices family needs assessment form and guidance specific for CSHCN and their family.

4. Incorporate CSHCN's siblings when developing service plans & goals for CSHCN and families

Best practices research recommends incorporating the whole family support network in service planning and developing goals for families. In addition to including grandparents and extended family members, siblings of CSHCN often take upon lasting responsibilities and, when age appropriate, should be involved in both short-term and long-term service planning and goal development.

TXICFW Recommends:

Establish guidance and processes to include the CSHCN's siblings (when age-appropriate) in service planning and goal development for short-term and long-term planning.

5. Strengthen collaboration & care coordination with providers

CSHCN have a variety of different types of providers for specialized resources that often include medical providers, therapeutic/occupational providers, resources from schools, durable medical equipment providers, and case managers. The ongoing collaboration and coordination of all providers is crucial to ensure resources and support is provided timely and consistently.

Case managers have a unique role to spearhead this collaboration across providers, since they have built relationships with providers and are already knowledgeable in navigating various systems. This provider collaboration also lays the foundation for an improved experience in the CSHCN's transition to adulthood across all providers.

TXICFW Recommends:

Strengthen collaboration and coordination among all providers, particularly among medical/health providers, school/educational providers, durable medical equipment providers, and case managers.

6. Establish consistency in transition age planning for CSHCN

Transition age planning is particularly challenging for CSHCN due to the lack of resources, providers, and programming available once CSHCN reach the age beyond eligibility. Additionally, discussing transition planning is difficult with caregivers since they are occupied with addressing the immediate concerns for their CSHCN and family. Best practices research recommends discussing transition often and early (beginning at 12 years old) and have all providers discuss transition planning with CSHCN and their family.

Currently, CSHCN providers are discussing transition planning differently and using various resources. Providers also expressed need for more training and support in transition age planning.

TXICFW Recommends:

Establish consistency in processes and guidance to conduct transition planning throughout the case management process. This process should involve the collaboration and coordination of all providers in transition planning early and often during the case.

Conclusion

The purpose of this Needs Assessment report was to gain an understanding of how CSHCN services are implemented and received by caregivers in Texas. This increased understanding will inform the CSHCN case management practice model development. Specifically, this Needs Assessment aimed to answer the following research questions:

1. What are the processes and protocols for providing case management to CSHCN?
2. What are the strengths and challenges in how regions are providing case management services to CSHCN?
3. What are the issues that need to be considered in improving each of these 4 domains of CSHCN care (Federal Standards of CSHCN)?
 - i. Identification, Screening, Assessment, and Referral
 - ii. Access to Care
 - iii. Medical Home and Care Coordination
 - iv. Community-based Services and Supports
 - v. Transition to Adulthood

The data collected through interviews/focus groups and the online survey by CSHCN staff and caregivers show that CSHCN and their caregivers confirm that this population is particularly unique in the number and intensity of needs, providers, and limitations to accessing care. Additionally, findings show that the CSHCN Services Program and case management services provided to families are crucial for CSHCN and their families who would otherwise not have healthcare options for their CSHCN.

Specifically regarding CSHCN case management, the Needs Assessment shows that each region and provider is conducting case management in

unique ways. Staff and caregivers discussed strengths in how they provide case management, such as DSHS eligibility specialists help assess for CSHCN's eligibility for different programs/benefits and submit applications, case managers conduct comprehensive family needs assessment and are confident in building trust and rapport with families, case managers have strong partnerships in their community, and CSHCN staff are adept in advocating for their clients and finding supports. The Needs Assessment findings also revealed challenges such as lack of CSHCN providers, burdensome paperwork and low-reimbursement rates that disincentivize providers from serving CSHCN with CSHCN benefit programs, and lack of consistent data collection and ability to retrieve data to assess progress towards goals. Taking into consideration best practices research, National Standards of CSHCN, and Needs Assessment findings, some additional areas of improvement include incorporating siblings of CSHCN in developing service planning and family goals, improved collaboration with the CSHCN schools and school systems, and improved process and consistent practices in transition planning with families.

future. The development of the practice model is currently underway with close collaboration with CSHCN family experts, professionals, and stakeholders.

Practice Model Advisory Groups

In addition to this research and examining best practices for CSHCN and case management, TXICFW has created two types of Practice Model Advisory Groups, one for CSHCN professionals and stakeholders, and one for family expert consultants. The family expert consultants are parents of CSHCN in Texas. One family group is conducted in English and one family group is conducted in Spanish. These advisory groups are held monthly and are used as a forum to gain feedback on the development of different components of the practice model. The goal of the advisory groups is to intentionally use collective and lived experience to align case management practices that empower families and promote self-determination, equity, and dignity for all children.



Looking Forward

The literature review, National Standards for CSHCN, and findings from this Needs Assessment will help inform the development of a case management practice model specifically for CSHCN programming implemented in Texas. The purpose of the CSHCN case management practice model is to standardize case management practices and ensure all services are high-quality, family-centered, and culturally responsive. The intent is for case managers to have a consistent roadmap for serving families, yet remain flexible enough to adapt as needed without compromising quality, and provide sustainable long-term use despite any organizational shifts or restructuring that may occur in the

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Appendix A: CSHCN Contractors

TEXAS REGION	ORGANIZATION NAME	CASE MANAGEMENT CONTRACT	FAMILY SERVICES COMMUNITY RESOURCES CONTRACT
REGION 4/5N	Angelina County and Cities Health District		✓
REGION 7	Any Baby Can-Austin	✓	✓
REGION 8	Any Baby Can - San Antonio	✓	✓
REGION 8	The Arc of San Antonio	✓	
REGION 11	Cameron County Public Health	✓	
REGION 11	City of Laredo Health Department		✓
REGION 1	Coalition of Health Services (Uniting Parents)	✓	✓
REGION 7	Heart of Central Texas		✓
REGION 4/5N	Northeast Texas Public Health District		✓
REGION 2/3	Open Arms (dba Bryans House)	✓	✓

The Children with Special Health Care Needs Project

REGION 9/10	Paso del Norte Children's Development Center	✓	✓
REGION 9/10	Sharing Hands - A Respite Experience		✓
REGION 7	Texas Parent to Parent		✓
REGION 6/5S	University of Houston		✓
REGION 6/5S	University of Texas Health Science Center - Houston	✓	✓
REGION 9/10	West Texas Rehabilitation Center		✓

Appendix B: Pre-Interview Form

Consent

Information about the Interview

This interview is part of a study is being conducted by researchers at The University of Texas at Austin (UT Austin). The researchers are getting information from case managers, supervisors, managers, stakeholders, and caregivers to understand opinions, experience, and observations of how families with children with special health care needs are connected to services. The goal is to understand what is working well and areas of improvement in how case management services are provided to families and children with special health care needs.

WHAT AM I BEING ASKED TO DO?

Participate in a 1 hour interview or 1.5 hours focus group with a UT Austin staff member over the phone or video.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

We believe that there is little risk for you to be harmed in this study. There is always a small chance that someone might look through your responses, but your name and any other information that would identify you and will not be written on any research form. You can skip any question you do not want to answer. Skipping questions or stopping the interview will not impact your relationship with the program, school, or the UT Austin research team.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

There are no direct benefits to you for participating in the study. However, there is a potential benefit that this information might help improve how case management is provided to families who have children with special health care needs.

DO I HAVE TO PARTICIPATE?

No, your participation is voluntary. You should only participate if you want to. You can decide to participate now but later change your mind. That is okay. If you decide not to participate, you will not hurt your relationship with the organization you work at or The University of Texas at Austin.

WILL THERE BE ANY COMPENSATION?

For caregivers: To thank you for participating in the study, you will receive an electronic \$25 gift card. This gift card will be e-mailed to you at the end of the interview. You will have the option to select which type of gift card you want (e.g., Amazon, Target, Walmart).

For staff and stakeholders: There will not be any compensation for participating in an interview for this study.

WHO IS GOING TO KNOW INFORMATION ABOUT ME?

This study is confidential and your responses to the questions will not be linked to your identity. Results will only be reported in aggregate form. If you choose to participate in this study, you will be audio recorded. All audio recordings will be stored securely and only the research team will have access to the recordings. Recordings will be kept for up to five years and then erased.

WHO DO I TALK TO IF I HAVE QUESTIONS?

If you have questions about the interview, contact Dr. Beth Gerlach, who is the lead researcher for this research project. You can contact Dr. Gerlach by email at beth_gerlach@utexas.edu. You can also ask any questions to your researcher who will be in contact with you before, during, or after your interview.

Do you agree to participate in this interview? By clicking "I agree", I acknowledge that I have been informed about this study's purpose, procedures, possible benefits and risks.

- Yes, I agree to participate
- No, I do not agree to participate

Pre-Interview Form

Please complete this short form about yourself. The information in this form is confidential and you may skip any questions you do not want to answer.

INTRODUCTION QUESTIONS

Prior to our interview, we are asking participants to complete this short form about yourself. The information in this form is confidential and you may skip any questions you do not want to answer.

1. Are you a caregiver of a child with special health care needs?

- Yes
- No

If "Yes" is selected, Caregiver Question Block will be displayed.

2. Do you work at agency that provides services or connect families to services for children with special health care needs?

- Yes
- No

If "Yes" is selected, Staff/Stakeholder Question Block will be displayed

Caregiver Question Block

ABOUT HEALTH CARE COVERAGE

1. What type of health care coverage does your child(ren) with special health care needs currently have? Check all that apply:
 - Children with Special Health Care Needs Program
 - Medicaid
 - CHIP
 - Medicare
 - Social Security Disability insurance (SSDI)
 - Private Health Insurance
 - Other: please describe
 - I do not have health care coverage for my child with special health care needs right now.

- I'm not sure what health insurance coverage my child with special health care needs has right now.
 - Prefer not to say
2. What type of health care coverage do you currently have? Check all that apply:
- Medicaid
 - Medicare
 - Private Health Insurance
 - Other: please describe
 - I do not have health care coverage for myself right now
 - I'm not sure what health coverage I have right now
 - Prefer not to say

ABOUT YOUR HOUSEHOLD

1. How many children under the age of 21 do you currently live in your household? (Please include biological, adoptive, foster, step-children, or any other child that depends on you for support)
- _____
2. Who else (over the age of 21) currently lives in your household? Check all that apply:
- My partner or spouse
 - My parent(s) or My in-laws
 - My siblings
 - My extended family (aunts, uncles, cousins, etc.)
 - Other, please describe:
 - Prefer not to say
3. What was your household income in 2019?
- Less than \$20,000
 - \$20,000 - \$34,999
 - \$35,000 - \$49,999
 - \$50,000 - \$74,999
 - Prefer not to say

Staff/Stakeholders Question Block

1. Do you work at the Department of State Health Services (DSHS)?
- Yes
 - No

If yes, display question #2. If no, display question #3.

2. Select which region you currently work in.
- Region 1
 - Region 2/3
 - Region 4/5N
 - Region 6/5S
 - Region 7
 - Region 8
 - Region 9/10
 - Region 11
 - Central Office
 - I'm not sure what region I work in
 - Other, please describe:
 - Prefer not to say

3. Which community organization do you work for? If you do not see your organization name, please write your organization's name.
- Angelina County and Cities Health District
 - Any Baby Can- Austin
 - Any Baby Can - San Antonio
 - The Arc of San Antonio
 - Cameron County Public Health
 - City of Laredo Health Department
 - Coalition of Health Services
 - Heart of Central Texas
 - Northeast Texas Public Health District
 - Open Arms (dba Bryans House)
 - Paso del Norte Children's Development Center
 - Sharing Hands - A Respite Experience
 - Texas Parent to Parent
 - University of Houston
 - University of Texas Health Science Center - Houston
 - West Texas Rehabilitation Center
 - Other, please describe
 - Prefer not to say

ABOUT YOUR JOB ROLE & EXPERIENCE (QUESTIONS SHOWN TO STAFF ONLY)

1. What is your current job role?
- Case Manager
 - Team Lead
 - Supervisor/Manager
 - Director
 - Advocate
 - Other, please describe:
 - Prefer not to say
2. What type of licensure do you have? Check all that apply:
- LBSW
 - LMSW
 - LCSW
 - MSSW/MSW
 - LPC
 - LMFT
 - LPN
 - RN
 - Other: _____
 - None
 - Prefer not to say
3. How long have you been in this current role?
- less than 1 year
 - 1 - 2 years
 - 3 - 5 years
 - 5 - 7 years
 - 8 or more years
 - Prefer not to say

4. How long have you been working with the children with special health care needs population?
- less than 1 year
 - 1 - 2 years
 - 3 - 5 years
 - 5 - 7 years
 - 8 or more years
 - Prefer not to say

DEMOGRAPHICS

1. How old are you?
- 18 – 24 years old
 - 25 – 34 years old
 - 35 – 44 years old
 - 45 – 54 years old
 - 55 – 64 years old
 - 65 – 74 years old
 - 75 years or older
 - Prefer not to say
2. What best describes your race/ethnicity? Check all that apply:
- American Indian or Alaskan Native
 - Asian or Asian American
 - Black or African-American
 - Hispanic, Latino/x, or Spanish Origin
 - Native Hawaiian or Other Pacific Islander
 - White
 - Prefer to self-describe: _____
 - Prefer not to say
3. What is your gender?
- Male
 - Female
 - Non-binary
 - Transgender
 - Prefer to self-describe:
 - Prefer not to say
4. What city do you currently live in? (Question only shown for caregivers)
- _____

Appendix C: Interview Guides

Staff & Stakeholder Interview Guide

Research Objective

To examine staff & stakeholders' perceptions about providing case management services and other services to families and children with special health care needs with particular focus on the following:

- Strengths and challenges of receiving case management for CSHCN;
- Access to care;
- Quality of case management services provided; and
- Transition age planning.

Opener

To start off, I'd like to learn about your job and the children and families for whom you provide services. Though you may serve families from different programs, we are specifically interested to learn about the services you provide to families with children with special health care needs.

Case Management / Work Experience

1. Can you walk me through how you provide services for a family?
 - a. Walk us through how families get connected to you.
 - b. Talk us through a typical first meeting.
(Assessments, types of services provided)
 - c. What do you typically do during follow-up meetings?
2. Compared to families you serve/have served, what makes providing case management different for families with a child with special health care needs?
3. What goals do you have as a [job role] for CSHCN?
4. What are some of the most helpful thing you have done for families?
5. What are issues that make it difficult to do your job and/or best serve families?
6. What supports do you need in order to more effectively do your job?
7. What areas of your job do you find most challenging? Why? What would help navigate these better?
8. Since the start of the COVID-19 pandemic, how have you continued to provide services to your cases?
 - a. What type of challenges did you experience when providing your services to families?
9. Can you describe any instances where you were unable to aid your cases due to COVID?

Next, I'm going to ask a few more questions about your experience providing case management services. We are interested in hearing about your experiences and opinions in order to understand what is working well and what can be improved.

About families served

1. Can you tell me about the types of health conditions experienced by the children you serve? (Physical & behavioral)
2. How would describe the range of severity of conditions/needs of the children & families you serve? (e.g., wide range of conditions & severities or fairly consistent on the types of

conditions/severity of conditions)

Next, I'm going to ask you about how families you serve are able to access the care they need.

Access to Care

1. On a scale from 1 to 5, how would you rate the ability to access the care children & families need (e.g., medical, behavioral, therapy, education)?
1 = no access to needed care; 5 = very easy to access needed care
 - a. Why did you rate it a [number]?
 - b. What would need to change to make it a [higher number]?
2. What is a type of care or service that families need that is challenging to access?
 - a. Why is it difficult to access that service?
 - b. What would make accessing that service easier?
3. What is a type of care or service that families are currently unable to access that would otherwise improve their wellbeing?
 - a. Why are they not able to get it now?
 - b. What would make it easier?

Next, I want to ask you about other supports families receive or you would like for them to receive, beyond necessary medical, behavioral, therapeutic care for the children and families you serve.

Community-based services & supports

1. Aside from medically/functionally necessary services, do you feel that families are being connected to and participating in community-based supports, for themselves or their children? Examples could be something like family-oriented activities, educational activities, social opportunities for you and your child, or parent nights out?
2. What type of help or support do families receive through their child's school? Or if they are not in school, what about early childhood intervention (ECI) or other programming?
 - a. Do you help with communicating/collaborating with the child's school? How so? (learning/care services at school)
3. What do you think gets in the way of families being able to participate in community-based services for their child or themselves?
4. What resources would be helpful for you to provide services to cases during the COVID-19 pandemic?

Next, we want to learn about how you help families plan for future events, like transition age planning for the child or unexpected events. Transition age planning is a process that helps youth with special health care needs and their families prepare for the move from childhood to adulthood in order for them to live as independently as possible as adults.

Planning: Disaster & Transition Care

1. Can you share how you discuss transition age planning with caregivers? What does that look like?
 - a. Is discussing transition planning an established part of your process?
 - b. When do you typically begin these conversations?
2. What are some challenges in addressing transition planning with caregivers?
3. How have you helped families plan for addressing their child's needs during any emergency/crises? (e.g., current pandemic, natural disasters, family crises)
 - a. How knowledgeable/competent do you feel about this topic?

4. What additional trainings would help?
5. What additional community collaborations would help?

We are at the end of this interview, but I wanted to give you an opportunity to share anything else or as ask us any questions.

Wrap Up

1. Did you want to share anything else with us?
2. Was there anything else we should have asked you?
3. Do you have any questions for us?

Caregiver Interview Guide

Research Objective

To examine caregiver's perceptions about receiving case management services with a particular focus on the following:

- Strengths and challenges of receiving case management for CSHCN;
- Access to care;
- Quality of case management services provided; and
- Disaster/crisis planning & transition age planning.

To start off, I'd like to learn a little bit about your child and the services you are currently receiving.

Opener/About the Family

1. Can you tell me a little bit about your child?
 - a. Age:
 - b. Health condition(s):
2. Can you tell us about the services and care that your child & family receive?
3. Do you have someone that helps you coordinate & manage these different types of care for you and your child?
 - a. What organization(s) is/are this person from?
 - b. How you were connected with or how did you learn about this person/organization?

Next, I'm going to ask a few more questions about your experience receiving case management services. We are interested in hearing about your experiences and opinions in order to understand what is working well and what can be improved.

Case Management Experience

1. Can you walk me through a typical visit that you would have with your case manager?
 - a. How often do you meet?
 - b. How long is each session?
 - c. Where do you meet (home, phone)?
 - d. What are some of the things the case manager helps you with?
2. What are some of the most helpful things that your case manager has done for you and your family?
3. Do you have any concerns about case management services that you receive?
4. Is there something you wished your case manager could help you and your family with?

5. What changes would you like to see in the way you or other families receive case management services?
6. How accessible/easy is it get a hold of your case manager when you need them?

Next, I'm going to ask you about your experiences in accessing care in the community/providers (e.g., medical care, schools, behavioral health resources, etc.) for your child's condition. We'd like to know areas where your needs are being met and areas that you need some help with.

Access to Needed Care

1. When thinking about resources in your community, what are some types of care or services that have been available and helpful to your family in meeting your child's needs?
 - a. Medical
 - i. With respect to medical care, can you talk about the differences you've experienced before COVID-19 and current day? If access to medical care was not possible, what were the challenges you encountered?
 - b. Behavioral
 - c. School
 - d. Respite
2. What is a type of care or service that you need for your child or yourself that is challenging to access?
 - a. Why is it difficult to access that service?
 - b. What would make accessing that service easier?
 - c. Can you highlight some challenges that occurred prior to COVID?
3. What is a type of care or service that you would like for your child or yourself that would improve your family's wellbeing (e.g., respite, socialization)
 - a. Why are you not able to get it now?
 - b. What would make it easier?
4. Other societal/community barriers:
Are you experiencing issues with housing stability, transport, food insecurity, access to medication, employment? Were these barriers in place prior to COVID?
5. Are there any other types of community supports like family-oriented activities, educational activities, social opportunities for you and your child, or parent night outs (pre-COVID).
6. What types of help or support do you receive through your child's school? If your child is not school aged, do you receive services through early childhood intervention (ECI) or any other program?
 - a. Does your case manager help you with participate with this service?
7. Aside from the services that your child receives, are there things that you or your family could benefit from? What would better support things for your child?

Next, we want to learn about how you and your case manager plan for future events, like transition age planning for your child or unexpected events. Transition age planning is a process that helps youth with special health care needs and their families prepare for the move from childhood to adulthood in order for them to live as independently as possible as adults.

Planning: Disaster & Transition Care

1. Which services and/or resources do you think are missing for your child during the COVID-19 pandemic?
2. How has your case manager helped you prepare your child for their transition to adulthood?
 - a. If not discussed: sometimes case managers talk to you at different times, and that is okay.

3. What is something your case manager can do or help you with to better plan for your child's future after they turn 18?
4. How have you and your case manager planned for addressing your child's needs during any emergency/crises (e.g., current pandemic, natural disasters, family crises)

We are at the end of this interview, but I wanted to give you an opportunity to share anything else or as ask us any questions.

Wrap Up

1. Did you want to share anything else with us?
2. Was there anything else we should have asked you?
3. Do you have any questions for us?

Appendix D: Additional Data

CSHCN Diagnoses Data

The data table below is from FY20 HHSC CSHCN Services Program data of the diagnosis among CSCHN clients served. Although clients may have multiple conditions, they are required to list a primary condition to receive services.

Diagnosis Categories	Diagnosis	Diagnosis N	Diagnosis %	Diagnosis Category N	Diagnosis Category %
Musculoskeletal disorders	Cerebral palsy	159	10.2%	281	18.0%
	Musculoskeletal disorders	71	4.6%		
	Craniofacial abnormalities (includes dental)	30	1.9%		
	Paralysis	21	1.3%		
Neurological disorders	Seizure disorders	163	10.5%	272	17.4%
	Other brain disorders	62	4.0%		
	Nervous systems malformations	31	2.0%		
	Neurodegenerative disorders	16	1.0%		
Endocrine disorders	Endocrine disorders	127	8.1%	185	11.9%
	Kidney disorders	58	3.7%		
Respiratory disorders	Respiratory diseases	82	5.3%	159	10.2%

The Children with Special Health Care Needs Project

Diagnosis Categories	Diagnosis	Diagnosis N	Diagnosis %	Diagnosis Category N	Diagnosis Category %
	Cystic fibrosis	77	4.9%		
Cancer/ Neoplasms	Neoplasms - Malignant	101	6.5%	113	7.2%
	Neoplasms - Benign	6	0.4%		
	Neoplasms - Borderline	6	0.4%		
Genetic Disorders	Chromosomal disorders	64	4.1%	99	6.4%
	Genetic disorders	35	2.2%		
Cardiac Disorders	Congenital heart disease	51	3.3%	84	5.4%
	Other Cardiac disorders	21	1.3%		
	Conduction disorders (includes arrhythmias)	11	0.7%		
	Cardiomyopathies	1	0.1%		
Blood disorders	Hemoglobinopathies	33	2.1%	78	5.0%
	Coagulopathies (includes hemophilia and clotting)	16	1.0%		
	Blood and bone marrow disorders	14	0.9%		

The Children with Special Health Care Needs Project

Diagnosis Categories	Diagnosis	Diagnosis N	Diagnosis %	Diagnosis Category N	Diagnosis Category %
	Vascular malformations	11	0.7%		
	Other vascular disorders	4	0.3%		
Congenital disorders	Congenital malformations	18	1.2%	61	3.9%
	Spina bifida	43	2.8%		
Auditory Disorders	Ear disorders - Hearing loss	56	3.6%	57	3.7%
	Ear disorders - Other ear disorders	1	0.1%		
Autoimmune & Immune disorders	Autoimmune disorders	35	2.2%	51	3.3%
	Immunodeficiencies	10	0.6%		
	Other immune disorders	5	0.3%		
	Lymph node, spleen, and thymic disorders	1	0.1%		
Visual Disorders	Eye disorders	46	3.0%	46	3.0%
Gastrointestinal disorders	Gastrointestinal disorders	24	1.5%	24	1.5%
Nutrition/Metabolic disorders	Metabolic and	18	1.2%	18	1.2%

Diagnosis Categories	Diagnosis	Diagnosis N	Diagnosis %	Diagnosis Category N	Diagnosis Category %
	Nutritional diseases				
Infectious disease	Infectious diseases	10	0.6%	10	0.6%
Skin/Dermatological disorders	Dermatological disorders	6	0.4%	6	0.4%
Reproductive disorders	Male/female reproductive disorders	5	0.3%	5	0.3%
Liver disorders	Liver diseases	5	0.3%	5	0.3%
Bladder/Urinary disorders	Bladder and Ureter disorders	5	0.3%	5	0.3%

Demographics of CHSCN Staff Participants

Staff Interview & Focus Group Participants

There were 32 interviews and focus groups conducted that were composed of 39 staff interviewees. There were 54 staff who participated in the online survey, and 4 were both caregivers of CSHCN and staff.

FIGURE D1: JOB ROLE, STAFF INTERVIEW PARTICIPANTS, N=39



FIGURE D2. JOB ROLE, STAFF SURVEY PARTICIPANTS, N=63



Note: Some participants selected multiple job roles.

FIGURE D3. LICENSURE, INTERVIEW STAFF PARTICIPANTS, N=37

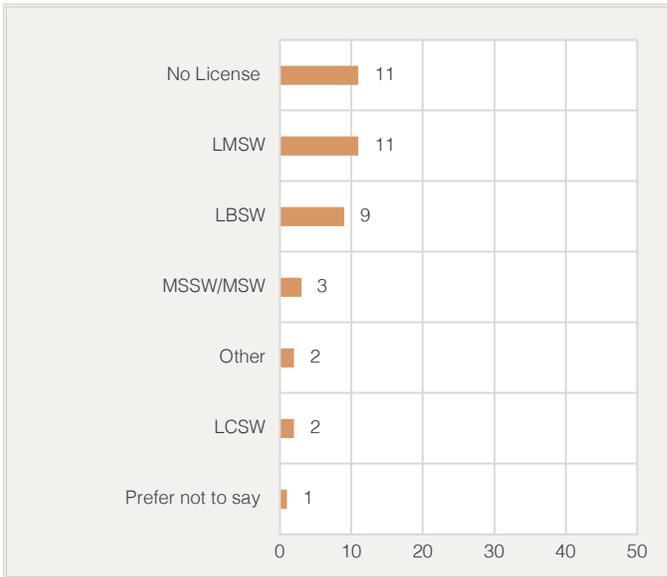


FIGURE D4. LICENSURE, STAFF SURVEY PARTICIPANTS, N=32

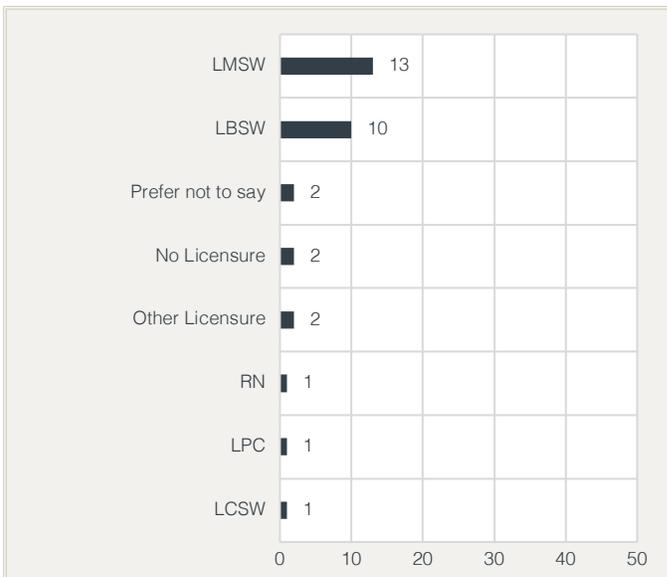


FIGURE D5. HIGHEST DEGREE COMPLETED, STAFF SURVEY PARTICIPANTS, N=51

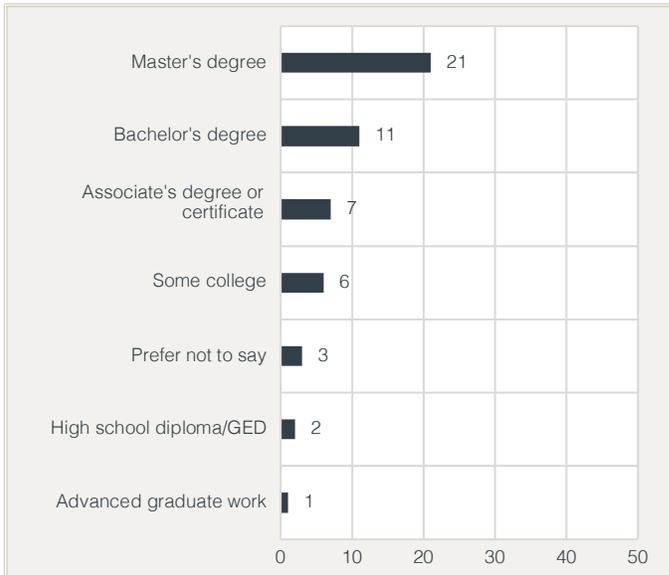


FIGURE D6. LENGTH OF TIME IN CURRENT ROLE, STAFF INTERVIEW PARTICIPANTS, N=38

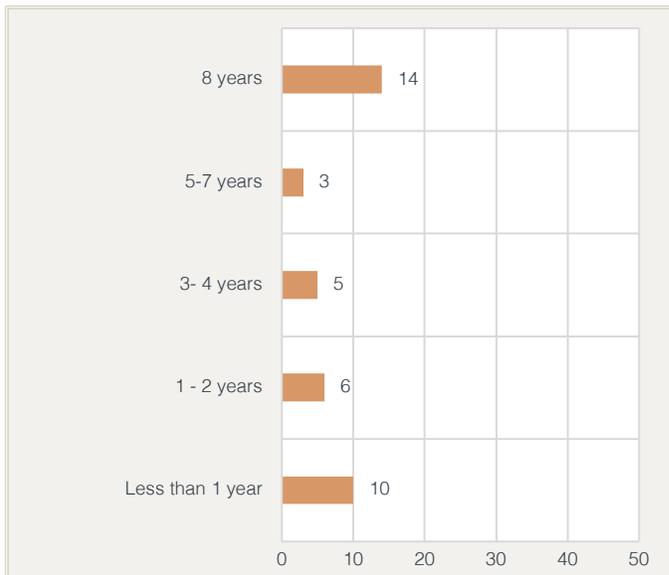


FIGURE D7. LENGTH OF TIME IN CURRENT ROLE, STAFF SURVEY PARTICIPANTS, N=51

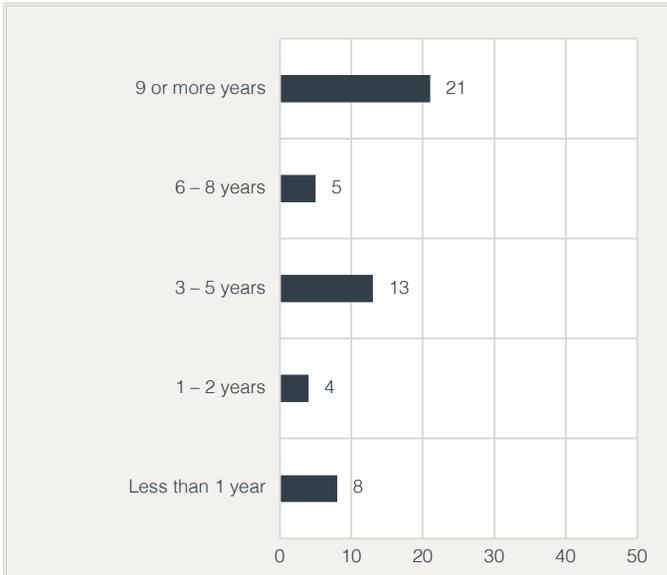


FIGURE D8. LENGTH OF TIME WORKING WITH CSHCN POPULATION, STAFF INTERVIEW PARTICIPANTS, N=38

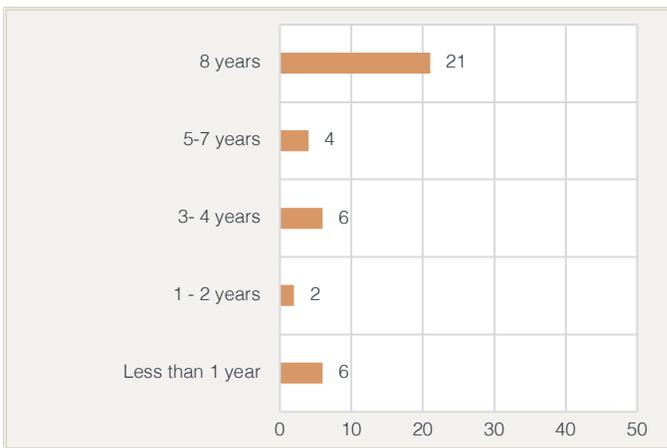


FIGURE D9. LENGTH OF TIME WORKING WITH CSHCN POPULATION, STAFF SURVEY PARTICIPANTS, N=51

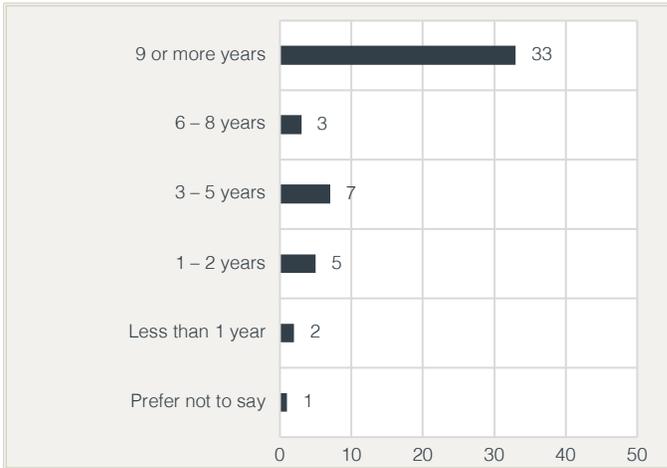


FIGURE D10. AGE, STAFF INTERVIEW PARTICIPANTS, N=39



FIGURE D11. AGE, STAFF SURVEY PARTICIPANTS, N=51

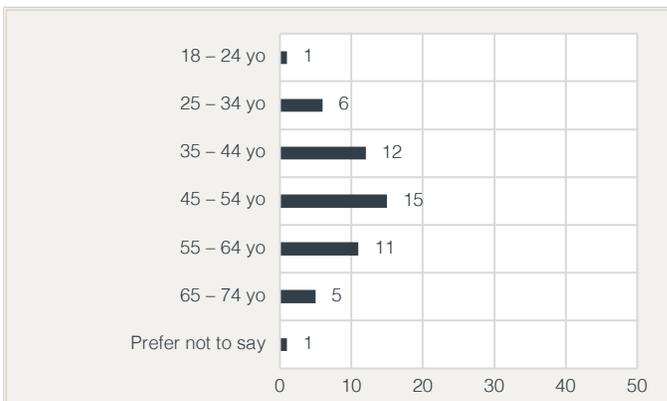


FIGURE D12. RACE/ETHNICITY OF STAFF INTERVIEW PARTICIPANTS, N=24

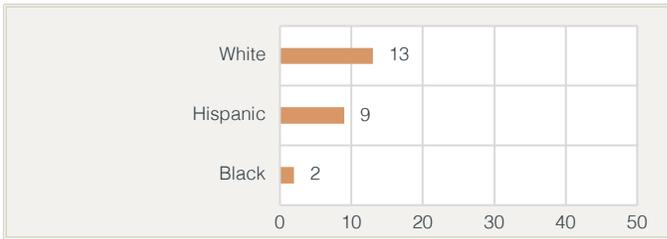


FIGURE D13. RACE/ETHNICITY OF STAFF SURVEY PARTICIPANTS, N=50

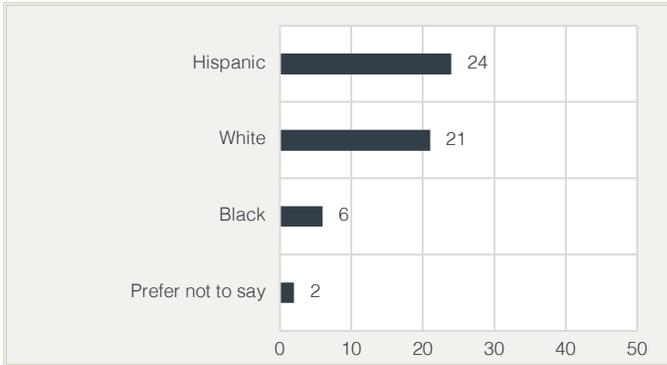


FIGURE D14. GENDER, STAFF INTERVIEW PARTICIPANTS, N=24

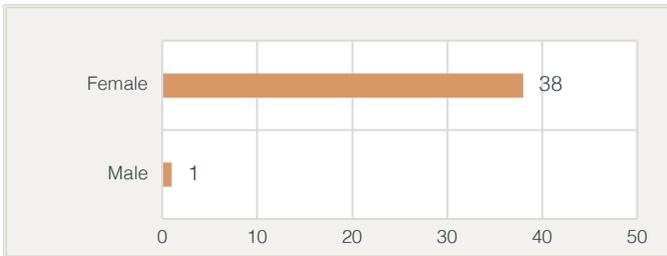
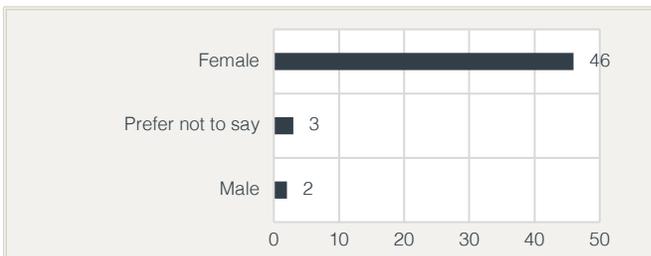


FIGURE D15. GENDER, STAFF SURVEY PARTICIPANTS, N=51



Appendix E: Summary of COVID-19 Impacts

The following information is a summary of the COVID-19 Impacts on CSHCN case management implementation in Texas that was presented each section of the Needs Assessment Findings section of the report.

COVID-19 Impacts to Identification, Screening, Assessment & Referral

Financial Strain on Families

Due to COVID-19 pandemic's public health social distancing measures, staff expressed challenges in receiving referrals from their usual sources, such as pediatric offices and other community organizations. Prior to the COVID-19 pandemic, CSHCN staff described that they would typically drop off leaflets at pediatric offices and conduct outreach to organizations to share information about CSHCN services. Staff indicate a concern that families who would otherwise be eligible are not currently receiving CSHCN case management services due to the challenges of outreach during the pandemic.

Caregivers and CSHCN staff also discussed families experiencing financial strain due to job loss because of the pandemic. Some staff discussed the lack of childcare for their CSHCN, forcing caregivers to quit their job to stay at home to take care of their children. CSHCN are particularly vulnerable to COVID-19 due to their comorbidities, and while there is some childcare available, it may not be safe for CSHCN to attend.

"The reason why I wasn't working at this time is because will all the pandemic and everything going on with the COVID I had to leave work and I had to ask for the FMLAs, the emergency leave, the FFCRA, so I could be with my son because I don't

have a daycare. There [are] no daycares around my area that can take care of my son. And, of course with the COVID going on nobody wanted to take care of my son because of course they don't want to be exposed to anyone...So, I don't receive any help. I don't receive any Medicaid. I don't have any help from the State or I have no help at all. So, when I met with her and she provided me all this, that was so helpful."

- Caregiver

COVID-19 Impacts on Screening & Assessment

Due to COVID-19, all case management meetings for screening and assessment with families occurred virtually, either by phone or video. Prior to COVID, those meetings would typically occur in person. The technology challenges (e.g., video meetings, telehealth appointments) among families served were mixed, and access to technology was related to whether families lived in rural or urban communities. Staff discussed that families in rural areas typically did not have access to internet, lacked computers and devices, and lacked knowledge of how to use devices.

"You have to let the families make that choice for themselves and recommend that they do their research on the providers. And that's hard, because sometimes they don't have access to the internet to do that. And there were times where you could say okay, if you go to the library, they have free computers and you can try to look at providers there. But right now, you can't even do that."

- DSHS Staff

In contrast, some staff discussed that most families had smartphones and were able to have meetings with case managers via Facetime or video conference. While in-person meetings were more ideal, they were able to switch to different virtual platforms to meet case managers and participate in telehealth appointments.

"We've been doing a lot of Zoom. We've been doing a lot of iPhone Facetime. And we've been doing a lot of phone calls and emails...Messenger on Facebook has been a good way for us to be able to see the children just like the iPhone has been a good way for us to see the children. [With] some families we still can't do that. We're actually just calling them and we're talking to them over the phone."

– Contractor Staff

Challenge in conducting outreach and gaining referrals

Staff discussed that the lack of in-person outreach and shifting priorities due to COVID-19 on healthcare clinics has slowed down the number of referrals they received from their established channels. While staff do continue to reach out to referral sources virtually, they report it is more difficult to make those lasting connections with providers, especially at schools, since COVID-19 has shifted those priorities.

"...before COVID, I loved going out into the community and letting them know about my services. But now, the challenge is we're huge on social media. Internally, I've talked to many of my coworkers. But it's been a challenge trying to get referrals at this moment."

– CSHCN Contractor Staff

COVID-19 Impacts to Access to Care

From this study, two themes emerged indicating how COVID-19 impacted how families' access care: 1) Shift to electronic paperwork and allowing authorized signatures from case managers and 2) shift to telehealth visits.

Ability to electronically submit paperwork/documentation

for the CSHCN Services Program.

Many CSHCN staff from interviews/focus groups and the online survey discussed how both the shift in allowing case managers to be the authorized signatory for families and the shift in ability to accept electronic versions of documents has been beneficial for timely submission of paperwork, and it is less burdensome of families. Staff discussed that they hoped this change in paperwork submission would continue.

"So, COVID has been a bit of a blessing and a curse... Because before COVID, we needed a lot of the original copies, for instance, the application [and proofs of documents]... Since COVID has happened... it's a lot easier to get proofs from these clients and their families because we're able to accept electronically submitted applications and other proofs."

– DSHS Staff

Shift from in-person healthcare visits to telehealth visits.

Caregivers and CSHCN staff discussed the shift from in-person health related visits to telehealth visits among families who had the technological capacity. Of the caregivers we spoke to, the shift towards telehealth visits was not preferred compared to in-person visits, particularly for physical health checks. However, there were a few examples from staff discussing how telehealth enables better care coordination among different providers by enabling the different providers to attend the same virtual visit.

"And we've been working on federal contracts to help do some telemedicine... And in some of the rural hospitals, I've seen a psychologist or mental health specialist from Dallas working with the family in [rural Texas city]. And they do it via telemedicine."

So, yes, that is a silver lining [of COVID]...Some of my families have commented to me as well that they like having these tele[health] visits with their family."

– CHSCN Contractor

One caregiver discussed that they preferred having in-person healthcare visits with their CSHCN's doctor and explained how telehealth visits were more difficult to communicate with the doctor.

"Well, the only difficult thing has been because it is a video call. It is not the same as when you go in-person, because the doctor checks him, weighs him. And it is better...And it is difficult because [my child] does not speak. It is difficult to help the doctor, to tell her, 'You know what, this and that happened.'" (Quote translated from Spanish)

– Caregiver

COVID-19 Impacts to Care Coordination

From the data collected for this Needs Assessment, there were no major COVID-19 impacts observed in regards to CSHCN medical home or care coordination.

COVID-19 Impacts: Community-based Services and Supports

Lack of respite care but ability for some families to gain in-home respite.

Due to COVID-19, many contracting organizations that have respite services for families are unable to provide respite. However, some CSHCN organizations have mentioned that some families are able to get in-home respite care. While any support is helpful, one contractor staff discussed the high stress levels due to all family members being at home all day.

"...And then some families would also receive financial support. So, they would find their own respite provider to do in-home respite for them. So, I think that that has completely stopped because of COVID, and now, then on top of that, the kids are all day at home with no opportunities to get out of the house, to go to school, or to go a summer camp, or an after-school program. So, I think the stress levels for a lot of the families are really high. So, they're getting no break."

– CSHCN Contractor staff

Lack of childcare for CSHCN.

Staff and caregivers discussed the lack of childcare options due to COVID-19, particularly for CSHCN. Since CSHCN are at a greater risk for COVID-19, families and childcare agencies alike were not accepting CSHCN at childcare agencies. Some caregivers also discussed the challenges of finding adequate childcare during COVID, especially with schools being closed during the beginning of the pandemic.

One caregiver highlighted the paradoxical impacts that come with the lack of childcare, challenges in securing a job, and the lack of school during to COVID:

"I'm not working now due to childcare. They didn't have nobody in this town that sees kids. They would only see school kids and it was only afterschool hours and [my child is] in school, of course... [my child] didn't go to school after spring break because of COVID and then they never went back...They wouldn't offer me the childcare unless I was already working, and I wasn't working before because I had quit my job [due to the lack of childcare]...So, you got to be working to get the childcare services or you don't get them."

– Caregiver

Access to COVID-19 grants and financial assistance to families.

Some staff discussed that COVID-19 has allowed for their organization to receive grants to provide basic needs assistance and/or emergency financial assistance for families. Staff were also appreciative of flexibility in contract requirements to provide emergency funds for families.

"...recently with the pandemic, we received some funding to assist families with basic needs. So, we have been able to assist families with mortgage, rent payment, utility assistance. Because we are dealing with families that have either lost their job, their hours have been cut. They've been suspended for two weeks or three just because of trying to limit the virus being spread...this is something that families were like, 'I've been limiting my kids as to what they eat.'"

– CSHCN Contractor staff

Shift to virtual parent support groups has expanded its reach.

Staff and caregivers discussed that while they prefer in-person meetings with other parents, having virtual parent support groups via Zoom has allowed for more families to participate

since travel is not required. One contractor discussed that during COVID-19, they started a Spanish-speaking Zoom parent group that has been very successful.

One caregiver described how conferences were typically far away and difficult to attend, but these opportunities are now available on Zoom.

"But I tell you that far away locations are very complex for us. We only have one car...I think that if it can be done right now that everyone is with Zoom and everything, if it can be done with Zoom, excellent." (Quote translated from Spanish)

Caregiver

COVID-19 Impacts: Transition & Disaster Planning

There were no major themes observed specific to COVID-19 impacts to transition planning. Rather, they were similar to COVID-19 impacts discussed earlier in challenges to accessing services and supports for families. For disaster planning, the experience of going through a pandemic has encouraged some staff to include pandemic preparedness in future disaster planning policies and protocols.



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