DRAFT – FY24 Children and Youth with Special Health Care Needs (CYSHCN) Annual Report

Maternal and Child Health

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1. Introduction

In the 2022 National Survey on Children's Health (NSCH), Texas had a slightly lower percentage of Children and Youth with Special Health Care Needs (CYSHCN) 17 and younger (20.6%) than the United States (U.S.) percentage (20.8%). The number of Texas CYSHCN in FY24 continues to grow compared to the 17.5% NSCH in 2020-2021. Additionally, 9.5% of Texas CYSHCN reported receiving care in a well-functioning system, compared to nationwide average of 13.1%. To impact National Outcome Measure of 17.2% (percentage of CYSHCN ages 0-17 who receive care in a well-functioning system), Texas Department of State Health Services (DSHS) identified three priorities through its comprehensive needs assessment (NA) process:

- Support comprehensive, family-centered, coordinated care within a medical home
- Improve transition planning and support services for children, adolescents and young adults, including those with special health care needs (SHCN)
- Increase family support and encourage integration of family engagement across all population health domains

DSHS uses three frameworks to engage and serve CYSHCN and address national and state performance measures described in this report. The National Standards for Systems of Care for CYSHCN (Version 2.0) outlines foundational principles that guide DSHS to better meet the needs of CYSHCN and their families:

- Children and families are active partners in decision-making at all levels of care.
- All CYSHCN services are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner.
- CYSHCN insurance coverage is accessible, affordable, comprehensive, and continuous.
- All care provided to CYSHCN and their families is evidence-based, evidence-informed, or based on promising practices where evidence-based approaches do not exist.

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The 2022 Blueprint for Change: A National Framework for a System of Services for CYSHCN offers a holistic lens to improve CYSHCN health outcomes and recognizes the extensive needs of families. A well-functioning system that integrates services, sectors, and providers is key for all CYSHCN to thrive and enjoy a full life from childhood through adulthood. The national Blueprint helps drive DSHS improvement work that centers on family experience in four key areas: health disparities, access to care, financing care, and well-being and quality of life.

In FY24, DSHS updated the CYSHCN Framework to align program activities with the national Blueprint's four critical areas. CYSHCN Framework examples include:

- Access to Services - DSHS funds case managers throughout the state to help CYSHCN and their families navigate complex systems and partners on numerous projects to promote a seamless transition to adulthood.
- Financing Services – The CSHCN SP and the Special Needs Dentistry Clinic help families pay for health and dental care.
- Health Disparities – DSHS assesses preventable factors that disproportionately affect CYSHCN and implements projects aimed at increasing parity.
- Family Well-Being and Quality of Life – The Family Advisory Council guides CYSHCN program and resource development. The Enhancing Systems of Care for Children with Medical Complexity (CMC) developed a care model centered on what families of CMC say matters most.

DSHS continuously integrates the three frameworks by:

- Conducting ongoing CYSHCN needs assessments, identify priorities, and implement programming responsive to findings
- Educating, raising awareness and building a shared understanding of coordinated, comprehensive systems of care for CYSHCN
- Establishing required quality measures and improvement activities for contracted services
- Supporting increased opportunities for family leadership and shared decision-making

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- Strengthening collaboration with Texas Medicaid to improve care and support for CYSHCN and their families
- Informing local, state, and national public policy to improve CYSHCN health outcomes

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2. Medical Home — Overall: Percent of children with and without special health care needs having a medical home

According to 2022 NSCH, CYSHCN made up 20.6% of Texas children 17 and younger. 2022-2023 NSCH data showed 37.9% of Texas CYSHCN received care in a medical home, compared to 39.7% nationally. Compared to 2022, there are more CYHSCN receiving care in a medical home in FY23 (increase of approximately 2.0%). In the 2023 Caregiver Outreach Survey, respondents reported 78.4% of caregivers organized their child's care themselves, suggesting a significant portion of this population was not receiving comprehensive care coordination. This same data showed 56.6% of respondents did not feel prepared for a medical emergency or disaster. Along with basic emergency preparedness, CYSHCN families must plan with clinicians for additional medications, medical supplies, power for medical devices and equipment, and accessible shelter. In response to these findings, DSHS developed six state action plan strategies to improve CYSHCN systems of care as described below.

State Action Plan Activities and Successes

Texas was one of five states selected for the National Center for a System of Services (NCSS) for CYSHCN Phase I Learning Collaborative to inform Blueprint implementation roadmap development. Launched in FY23, the two-year project co-led by DSHS and Texas Parent to Parent (TxP2P) aims to explore, plan and implement innovations to transform systems based on what matters most to CYSHCN families. Texas team members include a CYSHCN parent and community public health leader, dentistry professor working with people with Intellectual and Developmental Disabilities (IDD), Texas Council for Developmental Disabilities (TCDD) staffer, a behavioral psychologist, and the team coach. The Texas project centers on CYSHCN quality of life and well-being for families having difficulty providing oral health care at home. During FY24 the team met regularly to plan innovative family-centered listening and learning sessions for FY25 implementation. DSHS supported team efforts by:

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- Identifying and recruiting oral health experts and public health colleagues to join the team
- Convening team meetings, participating in national events, and completing the annual progress report
- Recording a video requested by team's oral health expert to highlight the Texas project and introduce national Blueprint concepts at the 2024 American Academy for Developmental Medicine and Dentistry's annual conference

In FY24, DSHS began developing 2025 CYSHCN Caregiver and Young Adult Outreach Surveys to monitor Texas' ongoing progress towards the three CYSHCN state and national performance measures: medical home, health care transition, and community inclusion. Questions developed for the survey align with the four Blueprint critical areas. DSHS engaged TxP2P to provide input and assist with Spanish translation. Medical home questions assess family and young adult experiences with accessing primary and specialty care, emergency preparedness, and care coordination.

DSHS shares medical home and additional resources in our monthly CYSHCN Resource Letter to a distribution list of 116 stakeholders (compared to 110 in FY23). The letter includes information about upcoming events, learning opportunities and other relevant resources for CYSHCN and families.

In FY24, DSHS prioritized health education and family and provider resources by distributing:

- "What Is a Medical Home: A Guide for Providers," for professionals working with CYSHCN and their families
- "Every Child Deserves a Medical Home: A Guide for Families," with information, tips, and resources to establish a medical home for their child
- "Children with Special Health Care Needs: A Resource Guide for Families," with statewide resource listings
- "What is the Children with Special Health Care Needs Services Program," an informational one-pager about the Health and Human Services Children with Special Health Care Needs Services Program (CSHCN SP)

Resource distribution improved for DSHS brochures and educational materials ordered online. DSHS made this process easier for health care providers, community organizations and families to access essential health

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resources. Materials are available in English and Spanish. In FY24, DSHS distributed medical home information, along with other resources, at the 2024 TxP2P Annual Statewide Conference reaching over 123 family and professional attendees. This is an attendee decrease of 50% from FY23 due to the conference occurring during the school year which impacted the number of conference attendees.

DSHS funds Texas Institute for Child and Family Wellbeing (TXICFW) at University of Texas School of Social Work to continue implementation and monitoring of case management practice model developed in FY23 for regional case managers and case management contractors. The curriculum consists of a practice model manual, interactive online training modules, and framework for CYSHCN Case Management Practice model trainer's guide. This curriculum helps case managers provide high-quality, family-centered and culturally sensitive services for CYSHCN and their families. TXICFW continued to distribute eight hours of social work continuing education credits to complete curriculum, including two and a half hours for ethics. TXICFW finalized the practice model trainer's guide which includes self-paced, in-person and hybrid materials and includes sample agendas with quality assurance evaluations. Seventy-one participants completed virtual trainings.

Participant evaluations showed:

- The training delivery was very or extremely effective (97.1%)
- The information covered was useful to their work with CYSHCN and families (98.1%)
- Participants will be able to implement new case management skills, tools, or awareness because of the training (98.4%)

In FY24, DSHS funded 16 community-based organizations (CBOs) for the fifth year of the family support and community resources (FSCR) and case management (CM) contracts. FSCR contractors provided a broad range of support services designed to meet specific local community needs. Services included respite, emergency planning, recreation and fitness programs, parent-to-parent networking and crisis prevention. FSCR services were available in all eight public health regions (PHRs) and covered 136 of Texas' 254 counties. CM contractors worked in partnership with CYSHCN and their families to assess needs, develop individual service plans, access state and local resources and help coordinate care. DSHS funded all PHRs to provide case management services.

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Each CM contractor met quarterly with their local PHR to confirm no service duplication and identify collaboration opportunities. DSHS conducted FSCR and CM virtual contractor training that provided guidance, education and technical assistance (TA). Sessions included a Title V overview, contract requirement information, new quarterly reporting process and UT Austin Case Management Practice Model. DSHS also required all grant-funded CM and FSCR contractor staff to take Texas Health Steps Online Provider Education (THSteps) courses on medical home, case management, and transition to adult care for CYSHCN.

In FY24, CM contractors provided 1091 clients (as compared to 962 in FY23- which is a 13.4% increase) and PHRs assisted 1,069 clients (as compared to 1,186 in FY23 which is a 9.9% decrease) with comprehensive case management by:

- Linking families to health care coverage, primary and specialty providers, therapies, transportation, medical equipment providers and social services
- Funding sources to pay for medications and critical medical needs
- Educating and empowering families to advocate as experts on their child's needs

Examples of FY24 CM and FSCR contractor activities to support medical home model:

Medical Home

In FY24, the City of Laredo partnered with a local school district to enhance their CYSHCN medical home model. This collaboration focused on equipping children with independent living and job training skills which are crucial for long-term well-being and autonomy. The local health department promoted professional development and public health awareness through activities such as providing food handler certifications. This multifaceted approach empowered children and their families with essential skills and knowledge. This initiative also helped children receive holistic care extending beyond traditional medical treatments, fostering an environment of growth, independence, and informed healthcare management.

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Care Coordination

The Cameron County Public Health Department (CCPHD) coordinated health insurance services by assisting with completion and submission of Medicaid applications for CYSHCN clients. The case manager used the submission confirmation page to coordinate Cameron County Indigent Health Program appointments mitigating a four to six-week wait. This coordination helped expedite client's appointments to apply for both Cameron Care and indigent care while in line for CSHCN SP services. Cameron Care is a public service for Cameron County residents who meet program financial requirements. The program assists with basic medical care, some specialty care, and up to three medications per month.

Emergency Preparedness, Safety, and Disaster Response

DSHS encourages CM and FSCR contractors to help families work with health care providers to prepare for emergencies by creating medication, equipment and accessible shelters plans.

In FY24, CM and FSCR contractors provided 2,896 emergency preparedness planning services including:

- Developing and updating preparedness plans
- Distributing emergency kits
- Registering families with State of Texas Emergency Assistance Registry

Any Baby Can of San Antonio's (ABCSA) Autism Service Program (ASP) revitalized and launched t a new home safety training program which focused on fire and water safety. This initiative aimed to enhance the preparedness of people with autism and conducted three training courses that garnered praise from both parents and community members for effectiveness and relevance. ABCSA case management staff took the training to better support clients and integrate these practices into care plans. ABCSA is proud of the positive impact this program had and remains committed to continuously improving community safety and support services.

Education and Resource Sharing with Medical and Dental Providers

Paso Del Norte Children's Development Center (PDNCDC) partnered with Young Men's Christian Association (YMCA) to give educational presentations on identifying developmental delays, positive discipline, autism characteristics, sensory processing, and other childcare worker related

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topics. These presentations raised awareness about the unique needs of children with developmental delays and disabilities to childcare agencies helping them to be better equipped and more willing to accept children with complex needs.

PDNCDC CM collaborated with a local dental provider to serve as a dental patient point of contact, for families to be better informed about the Medicaid Buy In for Children (MBIC) program. wMBIC provides access to both medical and dental care to help meet preventive and essential oral hygiene needs. The PDNCDC provided details about the MBIC program, as well as a referral system that helped families connect to case managers for application information and assistance. This helped families understand more about the MBIC program allowing for continuous access to necessary dental hygiene and preventive care services.

In FY24, TxP2P, the state's Family to Family Health Information Center and Family Voices affiliate, offered their medical education (MEd) program virtually to 94 medical students and residents (an increase from 48 in FY23). This program helps medical students and residents gain a deeper understanding of CYSHCN families and expands the informed physicians and allies base. A diverse group of family faculty who were trained in the program learned, through home visits and personal interviews, first-hand the daily challenges CYSHCN families face. Participation included interactive visits with CYSHCN and their families and discussions with parents on difficult topics. Parents shared insights on receiving their child's diagnosis, difficulties understanding and navigating complex systems, and ongoing service access challenges.

In FY24, DSHS approved funding for a Complex Care Fellowship Project to launch in FY26. This innovative training initiative will help address the critical shortage of providers willing to care for children and adults with complex, childhood-onset conditions. Led by the University of Texas Southwestern, the project aims to cultivate the next generation of expert clinicians dedicated to providing compassionate, comprehensive, and family-centered care to children with medical complexity (CMC).

The CYSHCN family experience survey (FES) gathers feedback from clients to improve CM and FSCR contractor services. In FY24, contractors received anonymous feedback to better understand client needs and enhance program planning and service delivery. The survey was distributed through email, print, and quick response (QR) codes. Overall, 97% of families in FY24 reported service satisfaction. Family reported services were:

- Accessible, family-centered, comprehensive services (99%)
- Coordinated services (96%)
- Culturally effective services (96%)
- Continuous services (99%)

DSHS funds Texas Health and Human Services Commission (HHSC) to administer CSHCN Services Program (SP), which provides health care benefits to qualifying income children under age 21 with special health care needs and people of any age with cystic fibrosis. Program assists with medical, dental, mental health care, prescription drugs, special therapies, case management, family support services, health care visit travel and insurance premium payments. CSHCN SP is the payor of last resort. Clients are placed on a waiting list if funds are insufficient to meet client demand and removed based on urgency of need, age, and application date. In FY24, 1,184 clients received benefits. Over 89% (1,056 clients) of people served had no other insurance coverage. Although HHSC administers the CSHCN SP, DSHS oversees the funding to ensure that funds are spent according to Title V guidelines and DSHS expectations. DSHS and HHSC met monthly to discuss program changes, share resources, and explore collaborative opportunities.

During FY24 DSHS continued funding the Phil and Karen Hunke Special Care Clinic at University of Texas Health San Antonio School of Dentistry (UTHSASD) which opened in February 2024. The clinic has 12 operatories with five designated for intravenous (IV) sedation. Spacious, private, and soundproof rooms have adjustable lighting and monitors for movies or music depending on patient preference. Larger treatment operatories allow room for caregivers, wheelchairs, and adaptive equipment. Soundproofing adjustable lighting help prevent overstimulation. Movies and music can be great distractions, provide comfort, and allow patients to make choices during their appointments. Unique features for patient comfort include a zen den break room and bubble wall water feature in the waiting room. The zen den is a quiet and safe space for patients who need a break from their dental appointment. The bubble wall is both pretty and relaxing. The clinic received a 100% satisfaction rate on a recent patient care survey.

In July 2024, rotations began for 218 students who successfully completed *Preparing for Special Care Dentistry* preclinical course. By end of FY24, 23 students participated in clinical rotations. Students presented case-based

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scenarios and learned through special care virtual reality simulations including visual, hearing, physical and cognitive disabilities.

Between February and August 2024, the clinic saw patients from 14 counties, three of which were designated dental health professional shortage areas. UTHSASD also:

- Participated in seven community events for patients with special health care needs and created a local health and services partner referral system
- Hosted a webinar for community providers, students, and faculty about treating patients with autism
- Presented poster "Using Active Learning to Engage Students' Understanding in Geriatrics and Special Care at Special Care Dentistry Association Virtual Summit
- Submitted a poster and oral presentation abstracts accepted for FY25 conferences

Research concluded for a study titled "The Impact of Sensory Adapted Dental Environment on Anxiety in Children with Sensory Processing Disorders: A Crossover Randomized Control Trial." This research, funded by DSHS, evaluated whether a Sensory-Adapted Dental Environment (SADE) reduces anxiety and improves behavior in children with Sensory Processing Disorders (SPD) compared to a Regular Dental Environment (RDE). SADE, the sensory-modified dental environment, incorporated sensory adjustments including dimmed lighting, calming sounds, absence of flavored materials, and tactile modifications designed to reduce sensory overload and improve comfort during dental procedures. The results showed the SADE significantly improved behavior and reduced anxiety in the study participants. This research furthers the body of knowledge that helps improve access to dental care for CYSHCN populations. The research was disseminated via an oral presentation and two poster presentations. A manuscript is in development.

The Health Resources and Services Administration (HRSA) selected two Texas teams for the Enhancing Systems of Care (ESC) for Children with Medical Complexity (CMC) demonstration project awards to improve quality of care and service experience for CMC and their families. Led by the University of Texas at Austin Dell Medical School and the Dell Medical Center Comprehensive Care Clinic (CCC), DSHS is a key member of the Austin-based team. Additional partners include TxP2P, HHSC Medicaid CHIP Services, a Texas Medicaid managed care organization and the developer of CCC's shared care plan of care technology platform. The clinic's highly

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engaged family workgroup guides every level of project design, implementation and evaluation. The five-year initiative launched in FY22 closely aligns with the national Blueprint and aims to advance integrated CMC care by:

- Supporting expansion and continuous quality improvement of Dell Children's Medical Center' Comprehensive Care Clinic's (CCC) innovative Whole Child Visit model
- Piloting an alternative payment model to help sustain Whole Child Visit model
- Evaluating and sharing findings to inform policy supporting cost-effective care integration, highlight health disparities and optimize health, quality of life and well-being for CMC and their families

The Austin team conducted experience groups with 30 Spanish-speaking caregivers and used Photovoice methodology to highlight differences and other daily challenges experienced by both English and Spanish-speaking CMC families. The project illuminated serious barriers the family workgroup identified in accessing private duty nursing and essential medical supplies (such as the right type and amounts of syringes). Personal photos, corresponding narratives, and an opportunity to meet participating families provided an effective approach to elevate issues to HHSC Medicaid CHIP Services policymakers who attended an in-person Photovoice exhibit. National partners invited the Austin team to meet with the Center for Medicare and Medicaid Innovation to share project learnings, bring forward challenges and propose solutions. The Austin team's systems improvement work was featured in national webinars and an in-person conference.

These issues became key focus improvement areas that will continue in FY25. Other Austin team accomplishments included:

- Expanding the CCC family workgroup to include 10 Spanish speakers based on earlier Family Engagement in Systems Assessment Tool (FESAT) findings showing a need for better CCC population representation
- Implementing alternative payment model between CCC and a managed care plan that pays the clinic a significantly enhanced rate for biannual whole child visits

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- Presenting project learnings at national forums (including 2024 Association of Maternal and Child Health Programs conference), ESC for CMC learning sessions, and CMC virtual café series webinars
- Participating in the invitation-only Center for Medicare and Medicaid Innovation Listening Session: Care Model Design for CMC. The Austin team presented systemic challenges, barriers, and opportunities to improve CMC care. Initial feedback showed Austin team's input was impactful

DSHS supported ESC for CMC project efforts by:

- Serving on Austin team's Program Steering Committee and three subcommittees to offer public health and CYCHCN expertise
- Helping to develop written materials and presentation for state and national audiences
- Participating in learning sessions with all demonstration sites and TA calls led by project's coordinating center and CMC experts
- Partnering to strengthen collaboration between Title V and HHSC Medicaid CHIP Services through a Sustainability Affinity Group data analysis project
- Identifying opportunities to share and scale Texas learnings

Texas participated as one of 10 states in HRSA CMC Collaborative Innovation and Implementation Network (CoIIN) ending in FY22. In January 2024, Pediatrics published "Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs: Supplement", featuring an article authored by the Texas CMC CoIIN team. Publication "Financing Policy Considerations from Texas to Optimize Care for Children with Medical Complexity" also highlighted the Texas team's learnings.

DSHS served on Mountain States Regional Genetics Network (MSRGN) which ended on May 31, 2024. MSRGN, an eight-state HRSA-funded collaborative, assisted people with heritable disorders and their families (particularly underserved populations) in accessing genetic expertise and quality care. The Texas MSRGN team included family members, TxP2P, nurses, genetic counselors, public health professionals, a geneticist and other collaborators. DSHS attended the 2024 MSRGN Annual Genetics Summit and offered ways

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to continue sharing resources to raise awareness about state genetic services. FY24 MSRGN Team Texas accomplishments included:

- Distributing postcards to 600 physicians to raise awareness of state's genetic services
- Exhibiting at the annual Texas Pediatric Society meeting
- Developing a sustainability plan to preserve the Texas team's family and professional resources on other Texas websites after the grant ended

DSHS promoted THSteps modules and provided subject matter expertise for new quick course Providing Texas Health Steps Services in Medical Home which replaced the Building a Comprehensive and Effective Medical Home module. In FY24, THSteps providers completed 7,127 modules (compared to 6,059 in FY23 which is a 15% increase) on Building a Comprehensive and Effective Medical Home and First Dental Home.

In previous years, DSHS served on the Texas Primary Care Consortium (TPCC) steering committee, which addresses systemic health care issues such as disparities, high costs, and lack of access. The committee included Texas hospital systems, state agencies, primary care practices, pharmaceutical companies, professional associations, and university representatives. In FY24, the Texas Primary Care Consortium restructured their committee and DSHS support was no longer needed.

Policy Council for Children and Families (PCCF) works to improve state's health, education, and human services systems' coordination, quality, efficiency and service outcomes. During FY24, DSHS served on the council with CYSHCN family members, community organizations, faith-based stakeholders and businesses. Meetings focused on ongoing and emerging issues impacting CYSHCN families. Members developed a legislatively mandated biennial report with systems improvement recommendations and provided to HHSC Executive Commissioner and Texas Legislature for FY25. The recommendations support national Blueprint vision and address CYSHCN state and national performance measures. DSHS attended PCCF and subcommittee meetings, served on the new member selection committee, and provided medical home model, transition to adulthood, and community involvement subject matter expertise.

In FY24, HHSC dissolved the STAR Kids Advisory Committee established in 2013 to advise HHSC on STAR Kids Medicaid managed care program issues,

policies, and decisions. DSHS served on the STAR Kids Transition Subcommittee until dissolution.

DSHS presented at 2024 Newborn Screening Education Conference, Nurturing Tomorrow: Giving Babies a Healthy Start. CYSHCN topics addressed: medical home, six components of a well-functioning system, CM and FSCR services, CSHCN SP and DSHS learning opportunities, and resource materials. The post-event survey reported positive feedback.

Performance Analysis

Objective 1: By 2025, increase the percentage of CYSHCN and their families who are provided education and support about receiving care within a medical home by 2% above baseline (medical home services baseline FY15 = 5,754).

Increasing medical home awareness and access remains a DSHS priority. DSHS participation in the Blueprint National Project, ESC for CMC, and other initiatives continued to improve medical home model recognition and implementation. The FY24 data point for this objective was 2,708 which is 53% below FY15 baseline. Although the amount is less than the baseline, program reached almost 400 more families than last year. DSHS attributes the overall decrease in case management clients served due to changes in Texas' managed care organization structure and increased cost per client statewide.

Objective 2: By 2025, increase the percentage of CYSHCN providers who are provided education about medical home by 5% above baseline (FY19 THSteps participant baseline = 313).

In FY24, 661 providers completed THSteps' medical home module (which is 111.2% higher than the FY19 baseline). FY24 was a decrease from FY23 (760) due to THSteps' online provider education accelerated promotion efforts concluded.

Challenges

Growth of Texas CYSHCN exacerbates statewide health care provider shortages particularly urban and rural area specialists. Waitlists for certain services affect many families in receiving essential supports.

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Opportunities

DSHS continues identifying opportunities to improve medical home access and care coordination through education and family support. DSHS will develop plans to increase clinician and other stakeholder involvement representing varying specialties and expertise to expand CYSHCN family support. Projects such as case manager training allow DSHS to educate professionals on the medical home model.

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3. Transition: Percent of children with and without special health care needs who received services necessary to transition to adult health care

The 2022-2023 NSCH shows 16.9% of Texas CYSHCN ages 12-17 received necessary adult health care transition services compared to 22.3% nationwide. The 2023 CYSHCN Caregiver Outreach Survey found 66.5% of caregivers with youth ages 12-17 did not feel prepared for their child's transition to adulthood (2.5% increase from 2021 survey). Respondents reported they had not prepared for their child's transition in the following areas: emotional needs, postsecondary education, and employment. To improve these findings, DSHS developed six State Action Plan strategies to increase the percentage of youth with special health care needs (YSHCN) who receive necessary adult health care transition services. Guided by these strategies, DSHS continued supporting numerous projects to improve transition outcomes.

State Action Plan Activities and Successes

In FY24 the DSHS Transition to Adulthood Learning Collaborative (TALC) met quarterly to advance transition knowledge. Members included family members, self-advocates, case managers, providers, educators, managed care organizations, community agencies, and academic centers. DSHS provided information on state and national transition initiatives, upcoming events, academic publications and new transition resources. Meeting topics included the HHSC Vocational Apprenticeship Program, housing solutions for adults with disabilities, the Texas Technology Access Project, and Texas Education Agency (TEA) transition updates.

In FY24, data from TALC post event surveys shows 98% of respondents reported TALC met their educational needs (compared to FY23 96%) which is a 2% increase. 100% said they would apply learnings to their current role (compared to FY23 93%) which is a 7% increase. Survey findings indicated overwhelming satisfaction with TALC content with slight improvement from FY23. Respondents shared how they planned to implement new ideas and suggested topics for future meetings.

DSHS focused on supporting families, clinicians, and other professionals by providing health care transition resources aimed at helping CYSHCN transition from pediatric to adult care. Free materials, available in English and Spanish, can be ordered or downloaded from the DSHS CYSHCN website.

In FY24 DSHS funded CM, FSCR contractors, and PHRs to prepare CYSHCN and their families for transition to adult health care. CM contractors must evaluate transition readiness for all clients ages 12 and older. Contractors provided 1,725 transition services. PHRs provided 269 CYSHCN transition services . DSHS required all DSHS-funded CM and FSCR contractor staff to take the THSteps CYSHCN transition training module. CM and FSCR contractors and PHRs helped youth, young adults, and their families plan for adulthood by offering:

- Connections to physicians willing to accept young adults with disabilities as patients
- Resource information, including Got Transition's readiness assessments
- Education and resources on post-secondary opportunities, vocational services, employment, finances, and independent living
- Help with completing Medicaid, Supplemental Nutrition Assistance Program, and other public benefits applications

Examples of FY24 CM and FSCR contractor activities to support transition to adulthood include:

Cameron County worked closely with a local independent living organization, vocational services, and area school districts to provide activities that are helpful and beneficial for clients to prepare for adulthood and independent living.

University of Houston, Families CAN offered virtual workshops on transition, health, emergency preparedness and community organizations that support families of children with disabilities. Workshops provided parents information to support their children as they transition to adulthood to receive services.

Coalition of Health Services, Inc. held their fifth Annual Route 66 Conference with sessions focused on emergency preparedness and mental health services for CYSHCN and their family members. The event had a total of 47 families and professionals in attendance. The local director for 2-1-1 in

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Amarillo discussed services available specifically for CYSHCN. Since the Panhandle area suffered wildfires and flooding in the past, discussion topics included websites to access medical information forms, State of Texas Emergency Assistance Registry (STEAR), and preparing for natural disasters. The conference also highlighted local behavioral health provider programs and the availability of in-house and virtual services for teenagers. Discussions included skills development, communication, self-care, and identifying the needs of children and youth. Several attendees noted a high level of satisfaction regarding conference topics.

Since 2019, DSHS and other state Title V programs, Got Transition, and National Alliance to Advance Adolescent Health built a consortium to promote health care transition (HCT) planning at school. Partnered with National Technical Assistance Center on Transition: The Collaborative, the consortium believes it is imperative to meet youth and their families through mandated special education transition planning process to improve HCT outcomes. In FY24, the federal Maternal and Child Health Bureau (MCHB) approved Wisconsin's TA request for Got Transition to lead bimonthly learning sessions and help advance HCT for students receiving special education services. Texas is one of the eight states in the consortium that examined state and federal transition laws and rules, reviewed current resources, shared best practices, and identified areas to incorporate HCT in special education. The group developed the poster "Partnering Together to Elevate Health Care Transition in Special Education Transition Planning" to present at Health Care Transition Resource Consortium Annual Symposium in early FY25. The National Center for a System of Services for CYSHCN invited the consortium to present at a Virtual Café in early FY25. DSHS supported consortium activities and partnered with TEA to advance HCT planning in Texas schools by:

- Collaborating with TEA to develop a new resource for educators "Improving the Health of Students in Texas Through Health Care Transition" for FY25 distribution
- Updating TEA's Transition and Employment Guide health chapter
- Co-presenting "Time for a Check-Up: Including Health Care in Special Education Transition" with academic colleague who later presented a poster with same title at a national conference based on years of DSHS collaboration. Seventy-nine educators attended the TEA presentation. Respondents to post-session evaluations reported the workshop met expectations, content was useful, and format was interesting, engaging, and well-presented.

DSHS promoted HCT planning in schools by:

- Co-presenting with a self-advocate and TxP2P's Executive Director Health Care Transition: Speak Up for What You Need for 21 attendees at the annual TxP2P conference. Content focused on legal changes at age 18, adding health goals in the Individual Education Plan (IEP), and empowering families to ask pediatric providers about HCT because too few clinicians discuss transition planning with patients. 73% of post-session evaluations reported satisfaction with content. 100% reported the information will help in caring for their child and 93% would recommend the session to others
- Sharing HCT resources
- Life transition fair attended by hundreds of students, families, educators, and other interested stakeholders
- Providing subject matter expertise to state's PCCF, which developed HCT recommendations for its FY25 legislative report

In FY23, DSHS initiated collaboration with the agency's School Health Program (SHP) to increase school nurse HCT knowledge and disseminate educational resources statewide. DSHS developed five actionable recommendations to promote school nurse engagement in HCT planning using the SHP Whole School, Whole Community, Whole Child model:

- Partner with DSHS to learn about transition from pediatric to adult-based care
- Add HCT resources and health care to SHP website including school-specific tools developed by Got Transition
- Promote intentional HCT planning at school particularly for transition-aged students receiving special education services
- Provide opportunities for teachers, transition specialists, school nurses, and other school personnel to learn about HCT and share evidence-informed programs, practices and policies on planning for health care transition in school
- Offer webinars in partnership with DSHS for students, families, educators, and school nurses on ways to incorporate health care goals into the IEP for transition-age students

In FY24, SHP and DSHS collaboration work continued. SHP helped distribute DSHS FY23 CYSHCN Outreach Survey and transition resources in a newsletter sent twice monthly to over 11,000 subscribers. SHP reported at

least one education service region (ESC) wants DSHS to present on HCT to school nurses in FY25. DSHS linked SHP with HHSC Medicaid CHIP Services staff able to respond directly to school nurse questions on program eligibility, waivers, and benefits. In October 2023, DSHS attended the 24th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care and served on advisory planning board. The event attracted 239 attendees and addressed the critical need to expand HCT skills and clinician knowledge. DSHS recommended speakers and funded scholarships for 29 family members to attend in-person.

Medicaid and CHIP Payment and Access Commission (MACPAC) invited DSHS to participate in a key informant interview focused on state HCT activities. Discussion centered on care transitions and specifically: identifying CYSHCN needing help, facilitators, barriers to care, family experience, and policy needs and considerations for different populations such as CYSHCN requiring high levels of care. MACPAC planned to share the findings in a future report.

The Meadows Foundation, which works to improve Texans' quality of life, invited DSHS to provide HCT expertise for an initiative to spark meaningful change in better meeting mental health needs of Austin area youth with IDD. The project "Examining Assumptions and Clinical Understanding Related to Mental Health Treatment for Youth with IDD" included three events to bring key stakeholders together and amplify youth voice. DSHS met periodically with Meadows Mental Health Policy Institute staff to offer program ideas and share resources. Meadows staff reported events were insightful, productive, and evaluations showed high participant satisfaction.

Performance Analysis

Objective 1: By 2025, increase the percentage of CYSHCN and their families who are provided education and support about transition from pediatric to adult health care by 2% above baseline. (FY15 Transition Services Baseline = 3,809).

In FY24, DSHS continued efforts to advance understanding of differences between pediatric and adult-based care, legal changes at age 18, and the importance of HCT planning. DSHS provided education, TA, and resources to transition-age youth and young adults, families, community-based contractors, service coordinators, social workers, educators, and other partners to improve HCT outcomes. CM contractors worked one-on-one with transition-aged youth, young adults and their families to assess readiness, improve self-management skills, and provide linkages to adult clinicians. The

FY24 data point for this objective was 1,725 which is a 54.7% decrease from baseline due to overall reduction in case management clients served by CM contractors. DSHS attributes this to changes in Texas' managed care organization structure and increased cost per client statewide.

Objective 2: By 2025, increase the percentage of pediatric and adult providers who are provided education and support about transition from pediatric to adult health care by 2% above baseline. (FY19 THSteps participant baseline = 1,084).

The FY24 data point for this objective was 1,048 which is a 3.3% decrease from baseline. Promotion of specific THSteps modules vary from year to year. The decrease could be due to THSteps decision to prioritize promotion of different modules in FY24.

Challenges

Barriers to clinical transition payment planning services, lack of adult providers willing to accept adults with disabilities, and pediatric provider reluctance to initiate transition planning conversations with youth and their families contributed to poor Texas outcomes. Dissolution of STAR Kids Advisory Committee and STAR Kids Transition Subcommittee in December 2023 removed platforms for addressing service delivery issues. Youth and their families do not learn about HCT through the school transition planning process and are unaware of many changes that begin by age 18.

Opportunities

DSHS requires CM contractors and PHR CM staff to complete the case management practice model to build skills and better assist youth to actively plan for changes in adult services. The STAR Kids Medicaid managed care program for CYSHCN requires service coordinators to actively engage youth and families in HCT planning beginning at age 15. Texas is one of eight states participating in Got Transition learning collaborative that aligns with the national Blueprint and centers on advancing HCT planning in schools. DSHS will continue working to promote health-related IEP goals for special education students, empower youth and parents to initiate HCT discussions with providers and expand strategic partnerships to further these efforts.

4. Community Involvement: Percent of CYSHCN and their families who participate in social or recreational activities with families who have children with or without disabilities.

According to the 2023 CYSHCN Caregiver Outreach Survey, 73.2% of respondents reported feeling isolated or lonely because of their child's disability and 37.8% did not feel a sense of belonging in their community. 81.7% of CYSHCN did not have access to inclusive after-school programs and 51.5% did not have access to inclusive preschool. Further, 58.9% of caregivers reported they needed respite care, but were rarely or never able to receive it. The three most common barriers to accessing respite care were lack of providers, inadequate finances, and lack of respite care knowledge which is consistent with 2021 survey findings.

State Action Plan Activities and Successes

In FY24, DSHS and TxP2P piloted the Family Advisory Council (FAC), supporting DSHS in providing insight for improving state programs, family support services, community resources, case management, and educational materials. FAC includes seven parents and caregivers from across the state representing rural and urban areas. FAC met virtually three times and once in-person at TxP2P Annual Conference in August 2024. Topics discussed included DSHS parent, caregiver, and youth surveys and the DSHS website.

During FY24, DSHS distributed 1,660 copies of "Communicating with and about People with Disabilities" resource in both English and Spanish at multiple forums. This resource offers practical tips for respectful communication with individuals with disabilities and is available for free.

DSHS developed social media content to further education, awareness, and outreach. In FY24, social media posts had 38,942 impressions (number of times social media content appears in someone's feed), reached 37,428 viewers (how many times people see a post) and achieved 535 engagements. Impressions decreased by 11,815, reach decreased by 8,679, and engagement (direct interaction such as a "like", a comment or a share)

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decreased by 432 compared to FY23. These decreases are due to less social media content published in FY24.

DSHS co-presented Peace of Mind Planning to educate Arc of Tarrant County families about a valuable tool detailing CYSHCN care need, abilities, likes and dislikes, medical information and more. This tool, called Letter of Intent (LOI), supports quality of life and well-being for both CYSHCN and their families now and in the future by communicating key information typically known only to primary caregivers. Afterwards, Arc invited DSHS to lead workshops to guide parents through LOI development. Starting in March 2024, five parents attended monthly sessions where they set individual goals and reported progress at each meeting. All parents made significant advances drafting critical LOI content for their child. Parents attributed success to DSHS guidance and structure and consistency of meetings. All participants asked DSHS to continue sessions in FY25.

DSHS presented Peace of Mind Planning for 29 parents, self-advocates, and professionals at Arc of Texas winter 2024 conference. Sixteen of 18 post-session survey respondents reported LOI knowledge increased "quite a bit" or "a lot" and would recommend session to others. DSHS co-presented Peace of Mind Planning at TxP2P annual conference with 30 attendees and a Community for Permanent Supportive Housing (CPSH) event with 21 attendees. 100% of TxP2P attendees responding to post-session evaluation reported satisfaction with content and expressed recommending session to others.

In FY24, DSHS continued to fund TXICFW to develop training and provide TA to CBOs serving families experiencing health disparities. TXICFW previously identified 4 PHRs with limited access to services and conducted interviews with area experts that provided leads on community organization partnership opportunities. To build relationships and capacity in FY24, TXICFW partnered with CBOs to offer educational events for communities served in the four regions. TXICFW was able to better understand each CBO's current capacity and assess future training needs. Additionally, TXICFW conducted interviews with current FSCR contractors and CBOs that offer FSCR to further inform development of a targeted training curriculum.

In FY24, DSHS funded FSCR contractors to provide opportunities for CYSHCN and their families to engage in community, educational, and recreational activities. FSCR contractors kept families updated on social activities, distributed tickets to community events, and offered virtual and in-person

programs. Events provided opportunities to improve sense of belonging, inclusion in community, and connect with other families.

DSHS contractors and PHRs helped CYSHCN and their families engage in community activities and improve family well-being by:

- Providing linkages to essential needed resources, such as housing and food
- Offering self-care workshops and support groups
- Hosting SibShops to offer siblings of CYSHCN peer support in a social setting
- Sponsoring community events to unite families and increase their sense of belonging

In FY24, CM and FSCR contractors conducted many activities to strengthen families and advance inclusion through the following:

Heart of Central Texas Independent Living Center (HOCTIL) conducted a sibling event called Significant Sibs: You're Seen, You're Heard, You're Significant. The event focused on honoring students at the University of Mary Hardin-Baylor (UMHB) that are siblings of someone with a disability. Each sibling received gifts and explored the Marek-Smith Center for Teacher Preparation, a new state-of-the-art special education training and instructional facility. Siblings honored commented they had never been recognized before and it was meaningful.

ABCSA expanded to include more parent training. New courses, including Crisis Safety and Personal Hygiene, address key areas of concern and were developed in response to parental requests. The Crisis Safety course equips parents to handle potential crises involving their children, covering topics like bullying, relationship safety and CPR. Personal Hygiene course emphasizes the significance of hygiene for children on autism spectrum. ABCSA noted that both courses have received strong support.

Any Baby Can of Austin had 37 children with special healthcare needs and their siblings attend Camp Grey Dove 2024. This camp allowed kids experiencing unique circumstances and special healthcare needs to fully participate in camp activities and have a memorable summer experience. Participants enjoyed swimming, ropes courses, interacting with animals and performing in the talent show. Participants wrote a petition to adults to make camp longer next year. Any Baby Can of Austin was honored to give

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kids a place to heal from challenges, to try new things, and build their self-esteem by engaging in camp activities.

PDNCDC partnered with a local organization called THINK180 to provide Science, Technology, Engineering, Arts, and Mathematics (STEAM) camps to children ages eight to 13. For the first time, PDNCDC offered a STEAM camp to children with and without disabilities and some activities accommodated children utilizing wheelchairs. Staff were available to provide one-on-one guidance to children with additional needs. All attendees received a medal and T-shirt for participating in the camp and the children stated it was a memorable experience.

DSHS staff serve as voting members of the Texas Council for Developmental Disabilities (TCDD). TCDD's mission is to create change to fully integrate people with disabilities into the community and have control over their lives. Families, self-advocates and representatives from disability organizations, University Centers for Excellence in Developmental Disabilities, and state agencies hold governor-appointed positions. Quarterly meetings focus on leadership development, addressing differences in employment outcomes, and public health and disability integration. Members discussed new and ongoing issues impacting people with disabilities, strategized future grants and policy priorities to address unmet needs, and awarded project funds. DSHS served on the Project Development Committee and contributed ideas for new initiatives to improve health care for people with disabilities. The first quarter meeting featured a DSHS contractor that implemented the national Blueprint into City of Laredo's public health program and launched a CYSHCN oral health project. This presentation led the Texas Blueprint Implementation Project team to choose an oral health innovation to improve care at home.

In FY24, DSHS served on Community Resources Coordination Group (CRCG) Statewide Workgroup. As of January 1, 2024, a total of 142 CRCGs comprised of public and private agencies helped children, adults, and families with complex multi-agency needs access services and covered 96.5% of Texas counties. DSHS contractors and PHR staff participated in local CRCG meetings to support families in or near crisis find and access vital services. DSHS attended quarterly CRCG Statewide Workgroup meetings, contributed newsletter content, helped select 2024 CRCG Recognition Award winners and served on a subcommittee to address training, communication, and data collection.

DSHS participated in the HHSC Caregiving Workgroup to represent CYSHCN families and help develop Texas Roadmap to Support Family Caregivers. When finalized, roadmap will identify actionable steps state partners can implement to improve caregiver quality of life and well-being based on five goals of the National Strategy to Support Family Caregivers:

1. Increase awareness and outreach
2. Build partnerships and engagement with family caregivers
3. Strengthen services and supports
4. Ensure financial and workplace security
5. Expand data, research and evidence-based practices

DSHS attended monthly workgroup meetings, shared resources to support CYSHCN caregivers and worked with teams to prioritize workable actions and determine feasibility to achieve project's stated goals.

In FY24, Transition Medicine Clinic at Baylor College of Medicine invited DSHS to join the clinic's new Patient-Centered Outcomes Research Institute project led by a research physician at Northwell Health Children's Hospital. Launched in 2022, the five-year project called "Future Planning and Well-Being for Individuals with Intellectual Disabilities and Family Caregivers" gives families of youth and adults tools to help confirm their child's quality of life and well-being now and in the future. Families are randomly assigned to one of two groups and either receive access to an online planning tool "Map Our Life" (MOL) or existing health promotion materials not related to future planning. Researchers planned to compare changes in family caregiver stress and well-being between the two groups. Doctors of family members with IDD created MOL with the goal of improving health and quality of life outcomes. In FY24, DSHS shared the national Blueprint for Change with Texas teams, attended quarterly stakeholder advisory group meetings with national partners, and helped plan participant recruitment.

Performance Analysis

Objective 1: By 2025, increase the percentage of CYSHCN and their families who are provided family supports and community resources by 2%. (FY19 FSCR services to families' baseline = 3,529).

DSHS staff and contractors provided services including parent networking, sibling support, and respite. The FY24 data point for this objective was 5,416 which is a 53.5% increase in CYSHCN and families served by FSCR.

Objective 2: By 2025, increase the percentage of providers of CYSHCN who are provided education and support on the provision of family supports and community resources by 2% (FY17 FSCR Provider Services baseline = 1,777).

FSCR contractors invited providers to attend training, workshops, and events that support CYSHCN in their community. The FY24 data point for this objective was 3,872 which is a 117.9% increase from the FY17 baseline.

Challenges

CYSHCN families have difficulty finding places that welcome and accept them. Like families across the U.S., Texas CYSHCN families struggle to find respite and inclusive childcare. Funding is insufficient to attract and retain respite care providers creating a worker shortage. Additionally, there are too few affordable childcare programs to meet statewide needs. Childcare and recreational activities are unaffordable to many CYSCHN families who already experience hardship paying for basic needs such as housing, food, and health care.

Opportunities

To better support family quality of life and well-being, DSHS will continue funding CYSHCN CBOs with high community engagement and knowledge on local, state, and national resources. DSHS will continue to provide ongoing TA to contractors to strengthen family engagement and fund CBOs in providing respite services and opportunities for inclusive recreational activities. DSHS will continue maintaining partner collaborative efforts and engaging in forums such as TCDD to raise awareness of unmet needs for CYSHCN.

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