DRAFT - PUBLIC COMMENT Children and Youth with Special Health Care Needs FY23 Annual Report

Maternal and Child Health

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TEXAS
Health and Human Services

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1. Introduction

In 2022, Texas had a slightly lower percentage of Children and Youth with Special Health Care Needs (CYSHCN) under age 18 (20.6%) than the U.S. (20.8%). The number of Texas CYSHCN continues to grow (National Survey on Children's Health/NSCH).

Additionally, 11.7% of Texas CYSHCN report receiving care in a well-functioning system compared to the nationwide average of 13.2%. To impact the National Outcome Measure of 17.2%(the percentage of CYSHCN ages 0-17 who receive care in a well-functioning system) Texas Maternal and Child Health (MCH) identified 3 priorities through its comprehensive needs assessment 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
- Increase family support and encourage integration of family engagement across all MCH domains

MCH uses 3 frameworks to engage and serve CYSHCN and address National Performance Measures (NPM) 11 and 12 and State Performance Measure (SPM) 1 described in this report.

The National Standards for Systems of Care for CYSHCN (Version 2.0) outlines foundational principles that guide MCH to improve outcomes for CYSHCN and 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.

The Children and Adolescent Health Branch (CAHB) framework complements national standards by improving Texas CYSHCN health and well-being through individual, health care systems, community-based, collective impact, and organizational strategies. Refer to the Child Health Annual Report for more information about the CAHB framework.

The June 2022 Blueprint for Change: A National Framework for a System of Services for CYSHCN offers a focused lens to view CYSHCN families holistically. In Fall 2023, Texas developed a new Texas MCH crosswalk to align Texas CYSHCN activities with the Blueprint's focus areas: quality of life and well-being, health disparities, accessing services, and financing services.

2. NPM 11: Percent of children with and without special health care needs having a medical home.

According to the 2022 NSCH, CYSHCN made up over 20.6% of Texas children under the age of 18. The NSCH data showed that 35.9% of Texas CYSHCN received care in a medical home, compared to 40.7% nationally. In the 2021 Caregiver Outreach Survey, respondents reported that 72% 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 49.5% of respondents did not have a medical emergency or disaster plan. Along with basic emergency preparedness, CYSHCN families must plan with medical providers for additional medications, medical supplies, power for medical devices and equipment, and an accessible shelter. In response to these findings, MCH developed 6 State Action Plan strategies to improve CYSHCN systems of care as described below.

State Action Plan Activities and Successes

The MCH-led Medical Home Learning Collaborative shared medical home model knowledge and best practices. Members attended quarterly webinars and received monthly updates with learning opportunities and resources. Fiscal year (FY) 23 webinars featured presentations on the Safe Riders Child Passenger Safety Program, the children's mental health crisis, and a children's mental health improvement project. Due to member feedback and duplicative MCH activities also covering these topics (such as the Texas Primary Care Consortium webinar series), MCH ended these learning collaborative webinars in FY23. MCH now distributes medical home resources in the monthly "CYSHCN Resource Letter" that has a distribution list of 110 stakeholders.

MCH staff developed and administered the 2023 CYSHCN Caregiver and Young Adult Outreach Surveys to monitor Texas' progress toward meeting the 3 CYSHCN state and national performance measures. MCH worked with stakeholders to disseminate English and Spanish versions. Staff used multiple strategies to boost reach and responses by:

- Mailing CSHCN Services Program (CSHCN SP) clients the survey.
- Creating an outreach toolkit with sample email/social media language and flyers for partners to distribute.
- Offering paper surveys.
- Sharing surveys on social media.

In FY23, MCH prioritized health education and family and provider resources by distributing:

- "What Is a Medical Home: A Guide for Providers," to professionals who work 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 and service listings.
- "What Is the Children Special Health Care Needs Services Program?" about the Health and Human Services CSHCN SP.

MCH changed its process by relocating brochures to the DSHS warehouse to ease resource ordering and distribution. Materials are free to download or order in English and Spanish.

MCH distributed medical home information at the Texas Parent to Parent (TxP2P) Annual Statewide Parent Conference to over 225 family and professional attendees. MCH shared medical home resources with 300 fathers, staff with male-serving organizations, and other professionals attending the Texas Fatherhood Summit.

MCH funds the Texas Institute for Child and Family Wellbeing (TXICFW) at the University of Texas School of Social Work to develop a case management practice model. The model will guide case managers towards high-quality, family-centered, and culturally sensitive services for CYSHCN and their families.

During FY23 TXICFW completed a practice model manual, interactive online training modules, and a framework for the CYSHCN Case Management Practice Model trainer's guide. TXICFW received approval to offer 8 hours of social work continuing education credits to complete the curriculum, including 1.5 hours for cultural diversity and 2.5 hours for ethics. TXICFW developed and conducted a DSHS case management supervisor statewide survey to indicate their preferred training modality. Of the 8 regions, 5 chose the two-day, in-person training, 2 chose the hybrid model, and 1 chose the self-paced, online option. Regional case managers and case management contractors gained access to the online training platform in February 2023, with 72 completing the training. Participant evaluations showed:

- The training delivery was very or extremely effective (100%).
- The information covered was useful to their work with CYSHCN and families (97%).
- Participants will be able to implement new case management skills, tools, or awareness because of the training (92.5%).

TXICFW conducted in-person training for 94 participants from June 2023 through August 2023. Participant evaluations showed:

- The training delivery was very or extremely effective (100%).
- The information covered is useful to their work with CYSHCN and families (100%).
- Participants will be able to implement new case management skills, tools, or awareness because of the training (98.6%).

MCH funded 14 community-based organizations for the 4th year of the Family Support and Community Resources (FSCR) and Case Management (CM) contracts. FSCR contractors provide services in response to local needs including respite, emergency planning, recreation and fitness programs, parent-to-parent networking, and crisis prevention. FSCR services were available in all 8 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 service plans, access state and local services, and help coordinate care. MCH also funded all PHRs to provide case management services. Each CM contractor met quarterly with their local PHR to confirm no service duplication and identify collaboration opportunities. To reinforce yearly expectations, MCH conducted a virtual FSCR and CM contractor training that provided guidance, education, and technical assistance. These sessions included information on American Disabilities Act, Texas Center for Disability Studies, and Title V overview. MCH also required all CM and FSCR contractor staff to take the Texas Health Steps Online Provider Education (THSteps) medical home, case management, and culturally effective health care trainings.

In FY23 CM contractors provided 962 (as compared to FY22 948 clients which is a 1.5% increase) clients, and PHRs assisted 1,186 clients (as compared to FY22 1,111 clients which is a 6.8% increase) 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.

FSCR and CM contractors conducted the following FY23 activities to support the medical home model described below.

Care Coordination

Bryan's House worked with several Dallas hospitals to help CYSHCN clients get health coverage, coordinate specialty care, and find resources to meet daily needs. While most CM appointments occurred at home, case managers accompanied CYSHCN families to medical appointments and special education meetings.

Cameron County Public Health Department (CCPHD) maintained its local clinic and Federally Qualified Health Centers partnerships to reduce medical access barriers. The contractor assisted clinic nurses and social workers with family follow-up to reschedule missed appointments and assess medical transportation and virtual visit needs.

Chronic Health Oriented Services for Niños (CHOSeN) Clinic, a practice providing comprehensive care to medically complex children and young adults, organized care for emergency room visits, hospital admissions, and follow-up after discharge. The CHOSeN Parent Support Group meets monthly to discuss topics important to parents, exchange information, resources, and provide peer support to parents.

Emergency Preparedness, Safety, and Disaster Response

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

In FY23 CM and FSCR contractors provided 2,980 emergency preparedness planning services (as compared to FY22 2,791 services which is a 6.8% increase) including:

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

CCPHD participated in an emergency planning community event focused on hurricane and evacuation preparedness. CCPHD also addressed preparedness for fires, floods, and school emergencies. 115 families received backpacks packed with a cooler, planning guide, emergency medical information form, flashlights, thermometers, and hand sanitizers.

The City of Laredo (COL) participated in Operation Border Health Preparedness, a 5-day community emergency preparedness event. Knowing the unique challenges CYSHCN families face during emergencies, the program tailored training to individuals with disabilities and specific medical needs. COL trained regional partners and medical home team members on specific emergency planning needs of CYSHCN families.

Education and Resource Sharing with Medical Providers

The Arc of San Antonio (The Arc) partnered with local hospitals to educate over 200 medical students on CYSHCN family needs. Topics covered public benefit programs, barriers encountered in accessing long term services, challenges for transition-age youth, and the medical home model. The Arc met individually with developmental pediatric residents at the local children's hospital and shared similar information to better prepare clinicians to care for CYSHCN.

TxP2P, the state's Family to Family Health Information Center and Family Voices affiliate, offered their medical education (MEd) program virtually to 48 medical students and residents. The program helps to improve understanding of CYSHCN families and expand the base of informed physicians and allies. A diverse group of trained Family Faculty invited participants into their lives through home visits and personal interviews to experience first-hand the daily challenges that CYSHCN families face. In FY23 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 and challenges finding support and navigating complex health, social service, and education systems.

In FY23, contractors distributed the Family Experience Survey to FSCR and CM clients to measure family experience with service quality and delivery satisfaction. Clients received surveys through email, print, and quick response (QR) codes. MCH sent surveys to each contractor with pre-paid return envelopes and online links to make responding easier. The FY23 FSCR return rate was 22% (as compared to FY22 24%, 2% decrease) and the CM return rate was 19.8% (as compared to FY22 16.4%, 3.4% increase). MCH attributes the decrease to typical yearly fluctuations and delays in receiving paper responses and survey burnout from families. Overall, 96% of families in FY23 reported service satisfaction which is a 6% increase from 90% in FY22. Families reported services were:

- Accessible, family-centered, comprehensive services (92%)
- Coordinated services (93%)
- Culturally effective services (95%)
- Continuous services (93%)

MCH funds the Texas Health and Human Services Commission (HHSC) to administer the CSHCN Services Program (SP) which provides benefits to low-income children under age 21 with special health care needs and people of any age with cystic fibrosis. CSHCN SP offers family-centered, community-based services that honor and respect families' cultural beliefs, traditions, and values. The program assists with medical, dental, and mental health care, prescription drugs, special therapies, case management, family support services, travel to health care visits, and insurance premiums. CSHCN SP is the payor of last resort. Clients are placed on a waiting list if funds are insufficient to meet demand and removed based on urgency of need, age, and application date. In FY23, 1,383 clients received benefits which is a 8.3% decrease from FY22 (1,508 clients). Funding availability and rising health care costs led to the FY23 decrease. Over 91% of those served had no other insurance coverage. MCH and HHSC meet monthly to discuss program changes and explore collaboration opportunities.

MCH was a key partner in the 2-year Complex Care Redesign Pilot (CCRP) which concluded in FY23. The pilot tested a care model to improve the health, well-being, and quality of life for children with medical complexity (CMC) and their families. The project built on Texas' past successes in the CMC Collaborative Improvement and Innovation Network (CoIIN) which ended in FY22. The child, family, and multidisciplinary care team (e.g., specialists, home health) participated in twice-yearly "Whole Child Visits" to develop a shared care plan based on what matters most to the family. Dell Medical School at UT Austin (Dell Med) served as the lead. The Comprehensive Care Clinic (CCC) at Dell Children's Medical Center, a primary care health home caring exclusively for CMC, was the innovation site. The CCC's highly active Family Workgroup, established to guide the CMC CoIIN, was integral to project design and implementation. The Family Workgroup developed survey questions to measure Whole Child Visit experience based on factors families identified mattered most.

FY23 CCRP achievements included:

- Enrolling English and Spanish speaking families at the pre-pilot stage to inform model design and conduct post-visit focus groups with families and care team members that led to refined patient goals and clinic workflows.
- Exceeding the initial pilot goal to enroll 350 children by 250% (n = 875) in the new, integrative, twice-yearly Whole Child Visits.
- Empowering families as equal partners in care plan development centered on their priorities and training clinicians on narrative medicine.
- Conducting an English and Spanish family survey with measures developed by the Family Workgroup to assess experiences with the new care model. Findings showed having 24/7 access to the clinic team led to lower emergency room utilization and statistically and clinically significant improvement in the care planning process.

- Finalizing an enhanced managed care organization per member per month payment rate to compensate the care team for the time and effort involved in preparing for the Whole Child Visit.
- Preparing publications and policy briefs, widely disseminating project results through Dell Med's international platform, and showcasing learnings through webinars that attracted CMC providers and national thought leaders.

Project researchers identified systemic quality of life and well-being barriers due to families experiencing significant unmet needs for home health care and mental health support.

MCH supported these efforts by:

- Serving on the project's core team and multiple subcommittees.
- Providing public health and CYCHCN subject matter expertise.
- Assisting in developing written materials.
- Identifying opportunities to share and scale Texas learnings and beyond.

The Health Resources and Services Administration selected Texas' CMC CoIIN application as 1 of 5 awardees for the new Enhancing Systems of Care (ESC) for the CMC grant. The 5-year project, launched in August 2022, builds on CMC CoIIN successes and seeks to improve the quality, coordination, and care and service experience for CMC and their families. The Austin team developed goals to advance integrated CMC care by:

- Supporting expansion and continuous quality improvement of the CCC's innovative Whole Child Visit model.
- Piloting an alternative payment model to help sustain the Whole Child Visit model.
- Evaluating and sharing findings to inform cost-effective care policy integration, highlight health disparities, optimize health, quality of life, and well-being for CMC and their families.

Dell Med and the CCC serve as project co-leads. CCC's highly engaged Family Workgroup guides project design and implementation. MCH, HHSC Medicaid CHIP Services, a Texas Medicaid managed care organization, and the developer of CCC's shared plan of care technology platform provide technical assistance and subject matter expertise. MCH helped draft the successful grant application, served on the team's Project Steering Committee and Policy Analysis Workgroup, and contributed to a HRSA project report, an executive summary, and other written materials. MCH attended virtual quarterly learning sessions with the 5 demonstration sites led by the project's coordinating center and participated in monthly team planning meetings with CMC experts.

Although the CMC CoIIN concluded in FY22, in FY23 the project director invited the Texas team to write an article on the 5-year initiative learnings for a supplement in the American Academy of Pediatrics publication, *Pediatrics*, highlighting the CoIIN. The team anticipates a FY24 publication date for its article "Financing Policy Considerations from Texas to Optimize Care for Children with Medical Complexity."

In FY23, MCH represents DSHS as a Texas Council for Developmental Disabilities (TCDD) voting member. TCDD's mission is to create change to fully integrate people with disabilities in their communities and exercise control over their lives. Representatives from disability organizations, University Centers for Excellence in Developmental Disabilities, state agencies, self-advocates, and family members serve in governor-appointed positions. Quarterly meetings and interim communications focused on legislative session prep and legislative activity updates. Members discussed emerging and ongoing issues impacting people with disabilities, strategized on future grant and policy activities to address unmet needs, and awarded funding for new and continuing projects. MCH served on the Project Development Committee and contributed ideas for new initiatives to improve health care for people with disabilities. The council subsequently funded projects to develop education, provider communications training and make health care decisions to empower people with disabilities and their caregivers.

During FY23 MCH served on the Mountain States Regional Genetics Network (MSRGN). The MSRGN, an 8-state HRSA-funded collaborative, assists 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. FY23 activities centered on increasing pediatric and primary care clinician outreach to improve state's genetic services awareness. A graphic artist designed themed postcards for distribution to 600 providers early in the project's final grant cycle (June 1, 2023 – May 31, 2024). Additional FY23 Texas team member activities and accomplishments were:

- Presenting on person-centered practices at the annual Genetics Summit.
- Expanding team membership to include 4 genetic counselors.
- Finalizing plans to exhibit at the annual Texas Pediatric Society meeting in early FY24.

Additionally, the MSRGN program manager and the state's genetic navigator presented "Resources for Genetics in Texas and Beyond" hosted by HHSC's Office of Prevention of Disabilities in Children which attracted 401 virtual attendees. MCH served on the Texas team's Recruitment of New Members Subcommittee and the Hope for Families subgroup, attended the 2022 and 2023 MSRGN Annual Genetics Summit, and participated in monthly team planning meetings. In August 2023, HRSA notified the regional genetics networks that this grant would end in May 2024.

In FY23 MCH provided subject matter expertise for THSteps Autism Spectrum Disorder: Screening, Diagnosis, and Management (ASD) module updates and promoted THSteps medical home modules. In FY23, THSteps providers completed 4,588 modules on Building a Comprehensive and Effective Medical Home, the First Dental Home, and Culturally Effective Health Care (as compared to FY22 5,956 modules which is a 23% decrease). The FY23 decrease is due to the Culturally Effective Health Care module being inactive for a part of the year resulting in fewer overall yearly completions. Refer to NPM 7.1 for more information about THSteps.

During FY23 MCH 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 includes representatives from Texas hospital systems, state agencies, primary care practices, pharmaceutical companies, professional associations, and universities. In FY23 the committee planned the Annual TPCC Summit which is a space for collective learning among diverse professionals to address prioritizing primary care in health care systems. FY23 sessions equipped 187 attendees with an understanding of today's health care challenges, best practices, and resources to improve Texans' health.

The Policy Council for Children and Families (PCCF) works to improve state's health, education, and human services systems coordination, quality, efficiency, and service outcomes. In FY23 MCH served on the council with CYSHCN family members, community organizations, faith-based stakeholders, and businesses. Meetings focused on ongoing and emerging CYSHCN and their family issues. Members finalized and submitted a legislatively mandated biennial report with systems improvement recommendations to HHSC's Executive Commissioner and the Texas Legislature. MCH attended FY23 PCCF and subcommittee meetings, served on the new member selection committee, connected the MCH Texas Early Hearing and Detection and Intervention program to the PCCF, and provided medical home model, transition to adulthood, and community inclusion subject matter expertise.

Oral Health

To increase the number of Texas specialty care dentists, CYSHCN SDG continued to fund the University of Texas Health San Antonio School of Dentistry in FY23 to establish a Special Needs Dentistry Clinic (SNDC). The clinic, which opened in February 2024, focuses exclusively on improving oral health for people with disabilities and other special health care needs. The SNDC founders collaborated with Texas public health agencies, community health organizations, and existing special health care resources to develop the SNDC.

In FY23, the SNDC officially became known as the Phil and Karen Hunke Special Care Clinic. The SNDC Community Advisory Committee continued to meet and provide guidance on clinic development. In addition to dental school faculty, committee members also included multiple patient advocate organizations including The Arc of San Antonio and disABILITYsa of San Antonio. SNDC established a clinic director search committee and hired a director with extensive special needs dentistry experience. SNDC designed new intake, pre-treatment, and patient satisfaction surveys. SNDC also conducted a retrospective review of patients at the dental school with intellectual and developmental disorders to establish clinic baselines and goals. The clinic updated its dental management software to reflect the comprehensive, interdisciplinary care that patients will receive. Additionally, the clinic developed a health care needs curriculum and clinical operations manuals and policies to prepare for student and resident rotations in the clinic.

A continuing education platform is in development. Community engagement activities also occurred in FY23 to spread clinical service awareness. This clinic will serve as a dental home for children and also for their future adult self. Further, all future dentists, dental hygienists, and most specialists will graduate with a greater depth of knowledge and clinical experience providing dental to patients with a broad array of special needs. This will help increase access to dental care for children and adults with special needs across Texas.

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 MCH priority. The CMC CoIIN, TPCC, and other initiatives continued to improve medical home model recognition and implementation. The FY23 data point for the "percentage of CYSHCN and their families who are provided education and support about receiving care within a medical home" was 2,363 which is 59% below the FY15 baseline. MCH attributes this to an 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 FY23, 760 providers completed the THSteps' medical home module which was 142.8% higher than the FY19 baseline. This increase over the baseline number is due to THSteps' Online Provider Education accelerated promotion efforts.

Challenges

Many Texas areas continued to experience provider shortages particularly specialists. Families had difficulty finding appointments or paying for transportation to appointments. Long Medicaid Waiver waitlists left many families struggling or unable to pay for health care.

Opportunities

MCH will continue identifying opportunities to strengthen education and family support with medical home access and care coordination. MCH will develop plans to increase clinician stakeholder involvement representing varying specialties, cultures, and expertise to expand CYCSCH family support. MCH will identify ways to partner with clinicians and other providers to help more CYSHCN families receive comprehensive, coordinated care. Projects such as case manager training allow MCH to educate professionals on the medical home model. The STAR Kids Medicaid managed care program for CYSHCN mandates care coordination requirements for all children receiving benefits. Focused child service coordination efforts lead to statewide CYSHCN care delivery and health outcome improvements.

3. NPM 12: Percent of children with and without special health care needs who received services necessary to transition to adult health care.

The 2021-2022 NSCH shows 23.2% of Texas CYSHCN ages 12-17 received necessary adult health care transition services compared to 22.1% nationwide. In the 2021 CYSHCN Caregiver Outreach Survey, 64% of caregivers with youth ages 12-17 did not feel prepared for their child's transition to adulthood. Respondents reported they had not prepared for their child's transition in the following areas: health care, postsecondary education, and addressing legal needs. To improve these findings, MCH developed 6 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, MCH implemented numerous projects to improve transition outcomes.

State Action Plan Activities and Successes

In FY23, MCH-led Transition to Adulthood Learning Collaborative (TALC) met quarterly to advance transition knowledge. Members included caregivers, self-advocates, case managers, providers, educators, managed care organizations, community agencies, and academic centers. MCH shared information on state and national transition initiatives, upcoming events, academic publications, and new transition to adult resources. FY23 meeting topics included technology to transform transition planning, TxP2P transition action groups, special needs trusts and other tools for future planning, and Texas Education Agency transition updates.

96% of post-meeting survey respondents reported TALC met their educational needs (as compared to FY22 94% which is a 2% increase) and 93% said they would apply the learnings to their current role (as compared to FY22 94% which is a 1% decrease). The data points show overwhelming satisfaction with meeting content with no significant difference from FY22. Respondents shared how they planned to implement new ideas and suggested topics for future meetings.

MCH provided health care transition resources in English and Spanish for families, clinicians, and other professionals. Materials are downloadable on MCH's website or can be ordered in large quantities at no cost.

In FY23 MCH co-presented on health care transition and future planning at 3 in-person events and 1 virtual event. Co-presenters included a young adult self-advocate, TxP2P's executive director, and a nonprofit executive director that helps CYSHCN leave nursing homes to live with families. MCH co-presented on future

planning at The Arc of Tarrant County's quarterly conference attended by 45 participants. Post-session surveys showed attendees valued the content and left with numerous implementation ideas.

MCH funded CM, FSCR contractors, and PHRs to prepare CYSHCN and their families for transition to adulthood. CM contractors must assess transition readiness for all clients ages 12 or older and provided 1,837 transition services (as compared to FY22 1,812 services which is a 1.4% increase). PHRs provided 595 CYSHCN transition services (as compared to FY22 721 services which is a 17.5% decrease). CYSHCN were eligible to receive multiple services during FY23. MCH required all MCH-funded CM and FSCR contractor staff to take THSteps' CYSHCN transition training module. CM and FSCR contractors and PHRs helped youth, young adults, and their families to 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, legal changes at age 18, finances, and independent living.
- Adult health care referrals including the Healthy Texas Women's program.
- Help with completing Medicaid, Supplemental Nutrition Assistance Program, and other public benefits applications.

FSCR and CM contractors conducted many FY23 activities to support transition planning.

In FY23 TxP2P offered 11 Pathways to Adulthood workshops for families and professionals (as compared to 8 workshops in FY22 which is an increase of 37.5%). Sessions addressed adult health care transitions, vocational training, higher education, employment, and social activities. In FY23, 257 parents (as compared to FY22 205 parents which is a 25.4% increase) and 5 professionals (as compared to FY22 17 professionals which is a 79% decrease) attended the workshops. The group forum allowed for idea and resource exchange, fostered a sense of belonging, and brought comfort to families sharing the adult transition journey together. TxP2P attributes the decline in professional participants to the elimination of night and weekend sessions and the increase in parent participation to topics such as housing which drew many attendees.

During FY23 Any Baby Can Austin (ABCAUS) presented in English and Spanish at the Destination...Life Transition Fair & Conference in Williamson County, Texas. ABCAUS presented to all county school districts to reach parents and adult transitioning youth. Topics covered education, employment, adult health planning, legal issues, finances, and housing. ABCAUS also presented at Texas State University to 40 youth between the ages of 14 and 21 on financial literacy, life skills, and adult transition resources.

In FY23 the Coalition of Health Services initiated the BEST Series (Building Essential Skills for Tomorrow) workshops for transition-aged youth, parents, and siblings. Six sessions addressed self-esteem, soft skills, body language, dress for success, hygiene, self-leadership, goal setting, and money management.

Heart of Central Texas Independent Living partnered with many school districts, colleges, and service providers in FY23 to host its 4th Annual Poss"Abilities" Job Fair. The event provided youth and young adults with disabilities an opportunity to find employment, plan for adult transition, and build interview skills to communicate with employers.

Since 2019, MCH, Got Transition, and the National Alliance to Advance Adolescent Health, worked to build a consortium among state Title V programs to advance health care transition planning at school. The consortium believes it is imperative to meet transition-age youth and their families through the federally mandated transition planning process for students receiving special education services. In FY23 Got Transition invited participating states to meet with the National Technical Assistance Center on Transition: The Collaborative (NTACT-C), the federal designee providing expertise for stakeholders of transition-age students with disabilities.

These meetings offered opportunities to learn about NTACT-C's activities, explore collaborative possibilities, and discuss addressing health in student education plans to improve transition outcomes. NTACT-C invited MCH to participate in "Ensuring A Meaningful Engaged Life: A National Discussion" with 45 local, state, and national stakeholders representing youth, families, education, vocational rehabilitation, health, academia, and others. The focus group meeting centered on creating sustainable system changes and improving outcomes for young adults with the most complex support needs. Based on participant input, in FY23 NTACT-C began drafting "Transforming Lives: A White Paper on Policy Changes for Youth with Complex Support Needs." The paper, expected to be finalized in FY24, will outline policy recommendations on accessibility, health care, and employment for youth and young adults with high support needs.

In FY23 MCH also provided subject matter expertise for developing and updating HHSC's Texas Health Steps Education continuing education module "Transition to Adult Health Care." MCH content recommendations were accepted including a citation from the new Blueprint for Change: A National Framework for a System of Services for CYSHCN.

MCH served on the FY23 planning committee and attended the 23rd Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care. The virtual conference attracted 260 attendees and addressed the critical need to expand the health care transition skills and clinician knowledge. HRSA's Division of Services for Children with Special Health Needs Deputy Director presented "Health Care Transition as a Federal Policy."

TxP2P used MCH funding to provide 31 scholarships for parents in FY23 as compared to 21 scholarships in FY22 and 4 for youth to attend the event as compared to 1 youth who attended in FY22. MCH participated on the advisory board to plan the Fall 2023 conference and contributed ideas for topics and presenters.

In 2023 MCH initiated a collaboration with DSHS' School Health Program (SHP) to increase school nurses' knowledge of medical transition and disseminate health care transition resources statewide. MCH developed actionable recommendations to advance health care transition knowledge and planning at school. MCH used the SHP's Whole School, Whole Community, Whole Child model to formulate the following recommendations:

- Partner with MCH to learn about the transition from pediatric to adult-based care.
- Add health care transition resources and health care to the SHP website including school-specific tools developed by Got Transition.
- Promote intentional health care transition 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 health care transition and share evidence-informed programs, practices, and policies on planning for health care transition in school.
- Offer webinars, in partnership with MCH, for students, families, educators, and school nurses on ways to incorporate health care goals into Individual Education Plans for transition-age students.

SHP vacancies in 2023 led to postponing recommendation implementation discussions until FY24. MCH periodically shared resources with SHP for dissemination in a newsletter distributed twice a month to over 11,000 subscribers.

In FY23, MCH offered subject matter expertise to TxP2P's Parent Advisory Committee (PAC) to establish a transition center to offer one-on-one support to transition-age youth and their families and develop a replicable intensive planning model. Members included parents, educators, and University of Texas at Austin Center for Disability Studies staff. In its 4th and final year, the PAC met every other month and worked to expand outreach, increase personal support networks, transition action groups (TAG), and plan project sustainability. MCH participated in these meetings and invited TxP2P to present on adult transition center activities during a TALC meeting resulting in greater TAG awareness and an increase in personal support networks.

Additional FY23 MCH efforts to support transition activities included:

- Responding to managed care organization service coordinators and transition specialist inquiries.
- Sharing transition resources and information requested by other state's CYSHCN colleagues.
- Participating in the STAR Kids Medicaid Managed Care Advisory Committee's Transition Subcommittee.

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 FY23, MCH continued efforts to advance understanding of the differences between pediatric and adult-based care, legal changes at age 18, and the importance of intentional planning. MCH provided education, technical assistance, and resources to transition-age youth and young adults, families, community-based contractors, service coordinators, social workers, educators, and other partners to improve health care transition outcomes. CM contractors worked one-on-one with transition-aged youth, young adults, and their families to assess health care transition readiness, improve self-management skills, and provide adult provider linkages. MCH participated in state forums to promote transition planning awareness. The FY23 data point for Objective 1 is 1,837, 51.8% below the baseline due to an overall reduction in case management clients served by CM contractors. MCH 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 FY23 data point for Objective 2 is 796, a 26.6% decrease from baseline. This module expired and was inactive for part of FY23 due to contracting issues which resulted in development delays. The updated course launched in August 2023.

Challenges

In December 2023, HHSC dissolved the STAR Kids Advisory Committee established to advise HHSC about STAR Kids Medicaid managed care program decisions. MCH served as a member of the STAR Kids Transition Subcommittee until its dissolution. Texas does not have an equivalent forum to improve STAR Kids program transition planning recommendations. 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.

Opportunities

MCH requires CM contractors to complete a training featuring an adult transition module and MCH-funded case manager training to initiate adult services transition planning with all youth beginning at age 12. This requirement will help youth and families learn about and actively prepare for adulthood system and service changes. The STAR Kids Medicaid managed care program for CYSHCN, launched in early FY17, requires service coordinators to actively engage youth and families in adult health care transition planning beginning at age 15. MCH will continue working with educators to encourage health care transition goal inclusion in school-based planning and expand strategic partnerships to further this effort. Texas is 1 of 5 states participating in the MCH Workforce Development Center's project to implement the Blueprint for Change and will continue work to align transition planning activities with the new framework.

4. SPM 1: 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 2021 CYSHCN Caregiver Outreach Survey, 43.7% of respondents reported feeling isolated or lonely because of their child's disability and 49% did not feel a sense of belonging in their community. Also, 77% of CYSHCN did not have access to inclusive after-school programs and 66% did not have access to inclusive preschool. Further, 26.9% of caregivers reported they needed respite care, but were never able to receive it. The 3 most common barriers to accessing respite care were lack of providers, inadequate finances, and lack of respite care knowledge.

State Action Plan Activities and Successes

In FY23, MCH distributed the resource "Communicating with and about People with Disabilities" in English and Spanish at multiple forums. This resource offers tips for respectful communication and can be ordered for free in large quantities.

MCH developed social media content for Instagram and Facebook in FY23 to further education, awareness, and outreach. Developmental Disabilities and Autism Awareness month were 2 of 5 topics highlighted on the DSHS social media platforms. MCH social media posts had 50,757 impressions (the number of times social media content appears in someone's feed), reached (how many times people see a post) 46,107 viewers, and achieved 967 engagements. Impressions increased by 6,500, reach increased by 29,067, and engagement (direct interaction such as a "like", a comment, or a share) increased by 400 compared to FY22.

MCH funds TXICFW to develop training and provide technical assistance to community-based organizations (CBOs) serving families experiencing health disparities. In FY23, TXICFW completed an environmental scan to understand disparities and services available in areas experiencing the most significant disparities. The team analyzed existing statewide data and used mapping to identify areas with limited access to services. This work culminated in the CSHCN Health Disparities Report. TXICFW met with experts to gather input on service gaps. Based on findings, TXICFW focused on 4 public health regions and held in-depth interviews with area experts.

During FY23, MCH funded FSCR contractors to help CYSHCN and their families engage in community life and prevent crises. FSCR contractors kept families updated on social activities, distributed free community event tickets, and offered virtual and in-person programs. These events helped families increase their sense of belonging, feel valued by their community, and connect with other families.

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

- Providing linkages to essential need resources such as housing and food.
- Providing smartphones and tablets to improve family telehealth access and support child educational needs.
- 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 FY23, FSCR and CM contractors conducted the following activities to strengthen families and advance inclusion.

Respite

MCH funded FSCR contractors to offer respite for families. In FY23, 866 CYSHCN families received a total of 37,331 hours of respite care. This represents an increase of 94.8% in respite hours, compared to FY22, during which 685 clients received 19,163 hours of respite care. The increase is attributed to contractors providing services for more clients.

Family Education, Support, and Networking

In FY23, TxP2P held its 18th Annual Statewide Parent Conference. 155 parents, 26 self-advocates, and 44 professionals attended. The event featured 56 breakout sessions (18 more than FY22) on mental health, special education, advocacy, parent leadership, medical transition, grief, Medicaid and Medicaid waivers, and caring for the caregiver. TxP2P offered a SibShop, a youth conference, and childcare. Over 2 days, 225 parents, self-advocates, and professionals attended. Conference evaluations showed attendees were very satisfied with the information and sessions provided and were glad to reconnect with other families in person.

TxP2P held in-person South and West Texas regional conferences in FY23 attended by 129 parents and 24 professionals, a 56% decrease from the previous year due to a third regional conference not being held. Local vendors shared resources with families. TxP2P held weekly virtual parent support groups in English and Spanish to connect families statewide.

Recreational Activities and Initiatives

For over 20 years, the Coalition of Health Services has offered the Wonderland Family Fun Day an amusement park with low-cost admission for CYSHCN and their families. In FY23, this inclusive event attracted 68 CYSHCN and 205 family members to enjoy rides and a picnic.

The University of Houston's Parent Education Project Families CAN program promoted inclusion by offering CYSHCN families free passes to enjoy the zoo, Museum of Natural Science, Children's Museum, and other community attractions. The contractor supported CYSHCN to attend swimming, karate, and performing and visual arts programs. These activities support the family unit and foster a nurturing environment to grow and thrive. Meaningful family engagement helped increase community awareness and understanding of CYSHCN families.

In FY23, MCH served on the Community Resources Coordination Group (CRCG) Statewide Workgroup. A total of 146 CRCGs comprised of public and private agencies help children, adults, and families with complex multi-agency needs and cover 96% of Texas counties. MCH contractors and PHRs participated in CRCG meetings to support families in or near crisis identify and access vital services. MCH attended quarterly CRCG Statewide Workgroup meetings, contributed newsletter content, and served on the workgroup's subcommittee to address training, communication, and data collection.

During FY23, HHSC's Aging Services Coordination program invited MCH to join a new Caregiving Workgroup to represent CYSHCN families and help develop the Texas Roadmap to Support Family Caregivers. The roadmap will outline action steps that state leadership, community stakeholders, and businesses can implement based on the 5 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

MCH attended monthly planning Caregiving Workgroup meetings, shared resources to support CYSHCN caregivers, and began working with the team on identifying actions to achieve the project's stated goals.

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).

MCH staff and contractors helped families navigate complex systems through parent networking, sibling support, training, and workshops. The FY23 data point for Objective 1 is 5,914, a 67.6% 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 invite providers to attend training, workshops, and events that support CYSHCN in their community. The FY23 data point for Objective 2 is 1,826, an increase of 2.8% from the FY17 baseline.

Challenges

Texas CYSHCN families, like those across the U.S., struggle to find respite and inclusive childcare. Funding is insufficient to attract respite care workers and there are too few affordable childcare programs for all children statewide. CYSHCN families have difficulty finding places that feel welcoming and accepting. 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

MCH will maximize family reach opportunities through DSHS social media channels. Providing technical assistance to contractors will help MCH maximize family engagement. To strengthen families, MCH will continue supporting CBOs that have CYSHCN family need expertise, high engagement in their communities, and are knowledgeable on local, state, and national resources. Community-based contractors will continue supporting families seeking respite and offering families inclusive recreation opportunities. MCH will continue engaging in forums such as the PCCF and TCDD to raise awareness of unmet needs and advance system improvement ideas.