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Children and Youth with Special Health Care Needs FY22 Annual Report

Maternal and Child Health

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TEXAS
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1. Introduction

In 2020-2021, Texas had a lower percentage of Children and Youth with Special Health Care Needs (CYSHCN) under age 18 (17.5%) than the U.S. (19.5%). The number of Texas children and youth diagnosed with special health care needs 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 13.7%. In an effort 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 three 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; and
- Increase family support and encourage integration of family engagement across all MCH domains.

Work in the above priorities align with the Title V state's priority needs.

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

First, the National Standards for Systems of Care for CYSHCN (Version 2.0) outline 4 essential and foundational principles which guide MCH work to improve outcomes for CYSHCN and their families:

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

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

Third, the June 2022 Blueprint for Change: A National Framework for a System of Services for CYSHCN provides a focused lens to view the holistic needs of CYSHCN and their families. In FY22, MCH began preparations for blueprint core principle and actionable strategy implementation to improve CYSHCN and family-serving systems. The blueprint's 4 focus areas are:

- Attainment of the highest level of health for all people;
- CYSHCN quality of life and well-being prioritization in the service system;
- Timely access to high-quality, easy-to-navigate services and supports; and
- Service system financing.

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

According to the 2020-2021 NSCH, CYSHCN made up over 17.5% of Texas children under the age of 18. The NSCH data showed that 29% of CYSHCN in the state received care in a medical home, compared to 42% nationally.

In the 2021 CYSHCN Caregiver Outreach Survey, respondents reported that 72% of parents and guardians organized their child's care themselves which suggests that a significant portion of this population was not receiving comprehensive care coordination from health care providers. The same data showed that almost half of respondents (49.5%) did not have a plan for an emergency or disaster. To improve these findings, MCH developed 6 State Action Plan strategies to improve CYSHCN systems of care. Guided by the strategies, MCH implemented numerous projects to improve medical home outcomes.

State Action Plan Activities and Successes

The MCH-led Medical Home Learning Collaborative (MHLC) increases and shares medical home model knowledge and best practices. Collaborative members attend quarterly webinars and receive monthly updates with relevant learning opportunities and resources. In fiscal year (FY)22, webinars featured presentations on the Texas Early Hearing Detection and Intervention program, the Texas Community Health Worker Program, the child mental health crisis, and state resources to support Texas families in accessing genetic services. These meetings included 66 unique attendees who reported the information met their educational needs and was applicable to their current roles.

In FY20, MCH established a state priority need to provide health education and resources for families and providers. To support this need in FY22, MCH distributed:

- "What is a Medical Home: A Guide for Providers" 1,371 times to professionals working with CYSHCN and their families;
- "Every Child Deserves a Medical Home: A Guide for Families," 3,404 times with information, tips, and resources for parents about establishing a medical home for their child ; and
- "Children with Special Health Care Needs: A Resource Guide for Families," 3,813 times with statewide resource and service listings.

English and Spanish pamphlets are available at no-cost and can be downloaded from the MCH website.

MCH funds the Texas Institute of Family and Child Wellbeing at the University of Texas School of Social Work (TXIFCW) to develop a case management practice model. The model will provide high-quality, family-centered, and culturally sensitive services for CYSHCN and their families. The project, guided by the National Care Coordination Standards for CYSHCN, has multiple phases:

- Phase I: Conduct an environmental scan and needs assessment to identify resources, links, and service gaps for CYSHCN and their families;
- Phase II: Design a practice model and train case managers; and
- Phase III: Continue technical assistance and program evaluation.

In FY22, Phase II continued as TXIFCW facilitated 3 regional advisory groups with English- and Spanish-speaking caregivers and case management staff. The groups provided feedback throughout the practice model development.

TXIFCW developed a manual for in-person trainings and online modules including a combination of video, audio, and interactive knowledge checks. Trainee groups will complete the training in-person, online, or in a hybrid format. In August 2022, 10 case managers attended an in-person pilot

training. Participants reported the training was informative and they looked forward to putting the model into practice.

Phase III will begin after case manager training completion. MCH extended the project through FY25 to continue quality assurance and sustainability efforts.

MCH funded 13 community-based organizations for the 3rd 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 Medicaid waivers, contract requirements training, a parent panel, and a guided collaboration and discussion session. Attendees reported the training:

- Generated ideas that they plan to put into practice (100%);
- Encouraged participation and interaction (96.8%); and
- Increased their understanding of the subject (100%).

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 FY22, CM contractors assisted 1,036 clients and PHRs assisted 1,111 clients with comprehensive case management services such as:

- Current COVID-19 health protocols, credible resources, testing center locations, and vaccine clinic information;
- Health care coverage, primary care and specialty providers, therapies including Applied Behavior Analysis, medical transportation, durable medical equipment providers, and social services linkages;
- Funding sources to pay for medications and critical medical needs;
- Healthy living and physical and emotional well-being education;
- Managing the emotional challenges of raising CYSHCN workshops; and
- Education and support to empower families to advocate as experts on their child's needs.

FSCR and CM contractors' conducted the following FY22 activities to support the medical home model.

Care Coordination

Chronic Health Oriented Services for Niños (CHOSeN) Clinic, a practice providing comprehensive care to CYSHCN and young adults with medical complexity, organized care for emergency room visits, hospital admissions, and follow-up after discharge. The CHOSeN Clinic developed a parent advisory board which will begin meeting in FY23. Parent advisors will provide input on clinic functions and service delivery.

West Texas Rehab Center (WTRC) collaborated with a local pediatrics group to hold monthly clinics with a pediatric occupational therapist, speech therapist, physical therapist, and WTRC staff.

Cameron County Public Health partnered with local clinics and Federally Qualified Health Centers to reduce medical access barriers. The contractor

helped clinic nurses and social workers follow up with families to reschedule missed appointments and assess medical transportation and virtual visit needs.

Emergency Preparedness, Safety, and Disaster Response

In FY22, CM and FSCR contractors provided 2,791 emergency preparedness planning services including:

- Hosting police and fire department staff trainings about effective interactions with people with disabilities;
- Developing and updating preparedness plans;
- Distributing emergency kits; and
- Registering families with the State of Texas Emergency Assistance Registry to alert local preparedness planners and first responders about potential CYSCHN needs during an emergency.

The City of Laredo (COL) connected the Laredo Police Department with the Deaf and Hard of Hearing (DHH) Center in Corpus Christi, Texas. COL scheduled a certified DHH instructor to train 508 officers and cadets on assisting and responding to DHH individuals.

Paso Del Norte (PDN) partnered with the Texas Department of Transportation on a car seat safety event called Spring Into Safety. PDN invited families to have their children's car seats inspected and attend a resource fair. During car seat inspections, inspectors deemed 11 car seats unsafe and provided corrections and support for future safety. Fourteen families received free car seats. The local health department shared cardiopulmonary resuscitation and other life-saving techniques. Families received identification kits to help law enforcement find a missing child. These kits give families peace of mind knowing the information needed for a search is readily available. Kits provided a space to keep a photo, report

physical characteristics, list medical information, and house a DNA sample. The kits also included a pre-inked fingerprint strip and a dental chart.

Education and Resource Sharing with Medical Providers

Any Baby Can of San Antonio (ABCSA) developed and cohosted an event with University of Texas Health Science Center (UTHSC) for 75 1st-year medical students. Experts presented tips for productive and positive office visits for people with autism. Three people with autism and their parents participated in a panel discussion and a small group practice activity. ABCSA's Client Specialist and her 15-year-old son, who is on the autism spectrum, gave feedback to the students.

Texas Parent to Parent (TxP2P), the state's Family to Family Health Information Center and Family Voices affiliate, offered their medical education (MEd) program virtually. The program helps medical students and residents gain a deeper understanding of CYSHCN families and expands the base of informed physicians and allies. A diverse group of trained Family Faculty invites participants into their lives through home visits and personal interviews to experience first-hand the daily challenges that CYSHCN families face.

In FY22, students in the MEd program participated in interactive visits with CYSHCN and their families and gained experience asking parents questions on difficult topics. Parents shared insights about receiving their child's diagnosis, difficulties understanding and navigating complex systems, and ongoing service access challenges. Fifty medical students and residents participated in the curriculum's communication skills section. All attendees who completed the evaluation agreed or strongly agreed that "MEd has increased my knowledge about the needs of children with disabilities and their families."

Through the Family Experience Survey (FES), administered by MCH, community-based contractor clients provided feedback on service quality. MCH uses the FES tool to track and improve contractor performance and client engagement. MCH required FSCR and CM programs to offer the FES to every family they provided services to at least once during the fiscal year. The survey is a continuous quality improvement strategy that leads to improved program planning and service delivery. The FES ties closely to the state priority need to increase family support and family engagement in programming.

In FY22, contractors distributed the FES to 4,471 FSCR and 1,036 CM clients to measure family experience and service delivery satisfaction. Clients received surveys by mail, email, website links, and quick response (QR) codes. MCH sent each contractor printed surveys, pre-paid return envelopes, and online survey links to facilitate distribution. The FY22 return rate was 24% for the FSCR survey and 16.4% for the CM survey reflecting a 5% combined increase from FY21. In FY22, findings showed most families received:

- Accessible, family-centered, comprehensive services (94%);
- Coordinated services (95%);
- Culturally effective services (97%); and
- Continuous services (93%).

Over 90% of families reported they were satisfied with services they received.

In FY22, MCH provided contractors their return rates, satisfaction scores, and respondent comments quarterly to increase survey response rates. MCH updated the survey cover page with family-friendly language to further improve response rates. The updated cover page includes QR code scanning directions. MCH partnered with a TxP2P family voice consultant to improve family-centered language and translation.

MCH funds the Texas Health and Human Services Commission (HHSC) to administer the CSHCN Services Program (CSHCN SP), which provides benefits to low-income children under the age of 21 with special health care needs. CSHCN SP also provides benefits to people of any age with cystic fibrosis but that is not funded by Title V.

CSHCN SP offers family-centered, community-based services that honor and respect families' cultural beliefs, traditions, and values, and 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 and places clients seeking health care benefits on a waiting list when there is not enough funding to support client demand. These clients are removed from the waiting list when state funding becomes available. Clients transition from the waiting list based on the urgency of need, age, and when they applied to the program. In FY22, 1,508 clients received services through the program. Of these clients, 92.6% had no other insurance coverage. CSHCN SP removed 529 clients from the waitlist during FY22 to receive services. MCH and HHSC meet monthly to discuss program expenditures, changes, and issues, as well as to explore collaboration opportunities.

The 5-year Children with Medical Complexity (CMC) Collaborative Improvement and Innovation Network (CoIIN) project allowed MCH to convene a diverse team of leaders and decision-makers. The state team

included the Dell Children's Medical Center's Comprehensive Care Clinic, TxP2P, University of Texas Dell Medical School policy experts, HHSC's Medicaid division, a Medicaid managed care organization, practicing clinicians, and health system researchers. Members shared a vision to improve the quality of life for CMC and their families' well-being. The CMC CoIIN Family Workgroup members held leadership roles, participated in project design and implementation, and developed outcome measures based on what matters most to families.

FY22 was the final year of the CMC CoIIN and activities focused on evaluation, sustainability, and disseminating findings. MCH contributed public health expertise, attended networking meetings, and attended the project's concluding event which highlighted the 10 participating state teams' successes. MCH attended STAR Kids Medicaid Managed Care Advisory Committee meetings to keep informed on issues, policies, and improvement efforts impacting CYSHCN and their families served by the program.

At AMCHP's 2022 conference, MCH collaborated with the CMC CoIIN Project Director at Boston University and Title V colleagues in Oregon and Kentucky to present "The Wind at Our Backs: Adaptive Title V Leadership and Resilience Through COVID-19 with Family-Partnered Quality Improvement Teams." Family Voices interviewed MCH and other CMC CoIIN members for an informational video "Real Talk: what does it really take to meaningfully engage with families" posted on the Family Voices website.

Over the CMC CoIIN 5-year duration, the Texas team identified the following systemic challenges to improving outcomes for CMC and their families:

- Every provider must conduct their own assessment and develop a care plan which creates information silos and added work for families;
- Justifying service eligibility and overseeing care delivery requires extensive resources, creating an immense administrative burden for providers and families; and

- No health home can sustain its costs within the current payment structure, which is insufficient to fund long-term, supportive, relationship-based care between the practice and families.

The CMC CoIIN success led to Texas receiving 2 more quality improvement grants, the Complex Care Redesign Partners (CCRP) pilot and Enhancing Systems of Care for CMC (ESC for CMC) grant. The CCRP pilot, a 2-year project launched in FY22, brought subspecialists and other providers into twice-yearly clinic appointments with families through telemedicine. MCH supported project framework development, quarterly partner meeting planning, and family engagement. Quarterly partner meeting topics addressed care quality for CMC and their families, financing Medicaid value-based care and measuring outcomes that matter to families. Each partner meeting began with a CMC parent sharing personal experiences and insights.

The Family Workgroup, first established to guide the CoIIN, participated in the CCRP's innovative care model design and named the "whole child visit" because "well child" is not an accurate CMC descriptor. The CCC piloted post-visit survey questions developed by the Family Workgroup to measure parent stress levels immediately following the visit, whether the child had a care plan, the current mood at home, and stress levels a week or more after the visit. Providers attending post-visit debriefs reported having greater insight into what mattered most to families. The clinic will use these findings to improve visits and empower family-driven care for children.

In FY22, the CCRP team:

- Conducted the pre-pilot with 10 families and multiple providers to gather input and measure experience;
- Presented project updates to the statewide Medicaid Managed Care Advisory Committee; and
- Organized and submitted a multi-stakeholder response to HHSC's request for information on a CMC alternative care model in the state's STAR Kids Medicaid managed care program.

The Texas CMC CoIIN and CCRP team was selected as 1 of 5 awardees for the ESC for CMC grant. The HRSA grant builds on the national CMC CoIIN accomplishments. MCH helped develop the successful grant application and committed to providing subject matter expertise and technical assistance for the project. MCH expects the ESC for CMC grant project to begin in October 2023.

MCH participated in the Mountain States Regional Genetics Network (MSRGN), an 8-state HRSA-funded collaborative. The network assists people with heritable disorders and their families, particularly underserved populations, access genetic expertise and quality care. The Texas MSRGN team included families, TxP2P, nurses, genetic counselors, public health professionals, the DSHS State Geneticist with the Newborn Screening Program, and other collaborators. In FY22, the Texas MSRGN team:

- Updated the Texas MSRGN webpage with new family and provider resources;
- Recruited a new pediatric practice that serves as a genetic champion for educating, equipping, and empowering pediatric and primary care providers to improve their ability to serve children impacted by genetic conditions; and
- Connected with researchers to explore collaborative opportunities with the Hope for Families subgroup which improves provider perceptions on disability and delivery of difficult news.

The team encountered challenges in identifying and reaching pediatric and primary care clinicians to increase awareness of the state's genetic services and share helpful resources with families. In response, the team will distribute postcards in FY23 to inform clinical providers statewide about the MSRGN, introduce the Texas team, and recruit more genetic champions.

MCH attended the November 2021 MSRGN Genetics Summit, the 2022 Summer Meeting, and monthly team meetings. MCH participated in website improvement activities, the Hope for Families subgroup, and 2022 Genetics Summit planning.

MCH also promoted THSteps medical home modules. In FY22, providers completed 5,956 modules on:

- Building a Comprehensive and Effective Medical Home;
- First Dental Home module; and
- Culturally Effective Health Care.

MCH provided subject matter expertise for Pediatric Hypertension: Screening, Diagnosis and Management module updates. Refer to NPM 7.1 for more information about THSteps.

MCH served on the Texas Primary Care Consortium (TPCC) steering committee which works to address systemic health care issues such as disparities, high costs, and lack of access. The committee included representatives from hospital systems, state agencies, primary care practices, pharmaceutical companies, professional associations, and universities. To provide continuous learning opportunities, TPCC presented webinars throughout the year on:

- Rebuilding the Foundation of Health Care;
- Powering Primary Care Advocacy;
- Balancing Pandemic Response and Sustaining Primary Care; and
- Primary Care 101: Laying the Foundation for Healthier Communities.

The TPCC steering committee planned the virtual Annual TPCC Summit. The summit is a space for dialogue and collective learning among professionals from diverse backgrounds to address primary care prioritization in health care systems. Sessions equipped attendees with a more comprehensive

understanding of today's health care challenges, best practices, lessons learned, and resources to improve Texans' health.

The Policy Council for Children and Families works to improve the coordination, quality, efficiency, and service outcomes provided through the state's health, education, and human services systems. In FY22, MCH served on the council with CYSHCN family members, community organizations, faith-based stakeholders, and businesses. Bylaws require that most members come from families with a child with a disability under age 26. Membership must also include at least 1 adolescent or young adult with a disability under the age of 26 who receives health and human services agency services. These requirements promote active family engagement, empowerment, and leadership development. In FY22, council meetings centered on ongoing and emerging issues impacting CYSHCN and their families. Members developed a legislatively mandated biennial report with system improvement recommendations. If implemented, the recommendations are likely to impact Texas' CSHCN performance measures.

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 an MCH priority. The MHLC, CMC CoIIN, TPCC, and other initiatives continued to improve medical home model recognition and implementation. The FY22 data point for "percentage of CYSHCN and their families who are provided education and support about receiving care within a medical home" was 3,227, which is 43.9% below the FY15 baseline. This is attributed to an overall decrease in case management clients served due to changes in Texas' managed care organization structure.

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 FY22, 696 providers completed the THSteps' medical home module which was 122.3% higher than the FY19 baseline.

Challenges

MCH capacity, staff turnover, and the pandemic impacted medical home initiatives collaboration statewide. Many Texas areas continue to experience provider shortages, most notably specialists. Families also had difficulty finding or paying for appointment transportation. Long Medicaid Waiver waitlists left many families struggling or unable to cover out-of-pocket health care costs.

Opportunities

MCH will continue to identify opportunities to strengthen medical home education and family support through partnerships and needs assessment results. MCH will continue strategizing to increase clinical stakeholder involvement with varying strengths, interests, and expertise to expand support for CYSHCN and their families. Opportunities exist for MCH to educate clinicians and other providers about supporting CYSHCN families within medical homes to expand capacities to provide comprehensive, coordinated care.

Projects such as the case manager training allows MCH to educate specific health care professionals on medical home implementation. The STAR Kids Medicaid managed care program for CYSHCN mandates health plan requirements for improved care coordination. 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 2020-2021 NSCH shows 16.9% of Texas CYSHCN ages 12-17 received necessary adult health care transition services compared to 20.5% 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 multiple areas including 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 FY22, the MCH-led Transition to Adulthood Learning Collaborative (TALC) met quarterly to improve transition outcomes. 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 resources. All attendees had the opportunity to contribute to the information exchange. The FY22 virtual meetings featured presentations on:

- The Peer Mentorship Program at Baylor College of Medicine's Transition Clinic;
- Texas Education Agency's new Transition and Employment Guide;
- Social and recreational activities for adults with intellectual disabilities;
- Alternatives to guardianship; and

- Integrating health care transition in special education with Got Transition's Health Research and Policy Associate.

A total of 94% of attendees responding to post-meeting surveys reported these meetings met their educational needs and that they would apply the learnings to their current role. Respondents also reported on how they planned to implement new ideas. MCH's challenge has been to maintain the high-quality content that TALC members have come to expect.

MCH distributed health care transition pamphlets for families and providers. Pamphlets are available in English and Spanish. All materials are available to order at no cost and are downloadable from the MCH website. MCH distributed 6,204 "What is Health Care Transition? A Guide for Youth and Families" brochures and 451 "What is Transition? A Guide for Providers" brochures.

In FY22, MCH presented or co-presented on health care transition and planning at 6 virtual events. Co-presenters included a young adult self-advocate, the state-funded special education transition services network project director, and an Institute for Person-Centered Practices co-founder. Presentation topics focused on incorporating health into school-based transition planning, parents as partners in health care, and using the Charting the LifeCourse trajectory tool to empower youth to identify and achieve their vision of a good life. Post-session surveys indicated that participants valued the content and took away implementation ideas.

MCH funded CM and FSCR contractors and PHRs to prepare CYSHCN and their families for transition. CM contractors assessed transition readiness for all clients over age 12. In FY22, CM contractors provided 1,812 transition services for CYSHCN. PHRs provided 721 CYSHCN transition services. CYSHCN were eligible to receive multiple services during the fiscal year. MCH required all CM and FSCR contractor staff to take the THSteps training on

CYSHCN transition services. CM and FSCR contractors and PHRs assisted youth and young adults and their families plan for adulthood by offering:

- Connections to physicians willing to accept young adults with disabilities into their practices;
- Resource information including Got Transition's website and transition readiness assessment tools;
- Education and resources about post-secondary opportunities, vocational services, employment, legal changes at age 18, financial needs, and independent living;
- Adult health care referrals including the Healthy Texas Women's program; and
- Help completing Medicaid, Supplemental Nutrition Assistance Program, and other public benefits applications.

The FSCR and CM contractors conducted the following FY22 activities to support supporting transition.

TxP2P offered 8 Pathways to Adulthood workshops for families and professionals throughout Texas. Sessions addressed the transition to adult health care, vocational training and higher education, employment, and social activities. Parents shared first-hand experiences to give insights to attendees new to the planning process. In FY22, 205 parents and 17 professionals including clinicians, social workers, teachers, and transition specialists attended the workshops. The group setting allowed parents to exchange ideas and offered them comfort in knowing they were not alone on the transition journey. TxP2P also held its Peer Parent Mentor training in English and Spanish to build parent-to-parent support.

The Heart of Central Texas Independent Living Center collaborated with 2 school districts, Temple College, University of Mary Hardin-Baylor, Texas Workforce Solutions Vocational Rehabilitation, Central Counties Services, and Workforce Solutions of Central Texas to host the 2nd Annual Temple

Area Poss-Abilities Job Fair. This event provided 57 youth with special health care needs the opportunity to find employment, learn about transition resources, and practice interview skills. High school students attended morning sessions and adults with special health care needs attended afternoon sessions.

Since FY19, MCH has met with counterparts in other states, Got Transition, and TxP2P to share ideas for incorporating health into school transition planning and learn about each participating states' efforts to partner with school teams. During the 3 FY22 meetings, the group analyzed participating states' school transition planning statute requirements for health or health care. None of the states had a specific requirement to address health as part of transition. Got Transition invited the group to meet with the National Technical Assistance Center on Transition: The Collaborative in early FY23 to learn and explore ways to improve transition outcomes.

MCH served on the planning committee of and attended the 22nd Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care hosted by the Baylor College of Medicine. The virtual conference attracted 313 attendees and addressed the critical need to expand the health care transition skills and knowledge of health care professionals. Featured topics:

- Advances in health care transition science and practice;
- Legal issues for young adults and their families;
- Improving mental health outcomes;
- Transition health disparities; and
- Health literacy.

A presentation given by a young adult with a chronic medical condition who shared lived experiences with social stigma and chronic grief was a conference highlight. TxP2P used MCH funding to provide 21 scholarships for

parents and 1 for a self-advocate to attend. Additionally, MCH participated on the advisory board to plan the Fall 2023 conference.

MCH supported collaborative partners improving transition-age youth outcomes. The Transition Medicine Clinic at Baylor College of Medicine recruited MCH to plan ways to disseminate its Peer Mentorship curriculum. MCH provided subject matter expertise to TxP2P's Parent Advisory Committee (PAC) for a project to build a transition center offering 1:1 support to transition-age youth and their families. Members included parents, educators, University of Texas at Austin Center for Disability Studies staff, and TxP2P. The PAC met monthly to strategize on outreach, expand TxP2P's personal support network model, and increase the transition planning group numbers for families.

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).

MCH efforts to increase understanding of the differences between pediatric and adult-based care, legal changes at age 18, and the importance of advance planning continued. 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 1:1 with transition-age 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 that increased transition planning awareness. The FY22 data point for Objective 1 is 1,812, 52.4% below the baseline because of an overall decline in case management clients served by CM contractors. This is attributed to changes in Texas' managed care organization structure.

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

The FY22 data point for Objective 2 is 1,306, a 20.4% increase from baseline.

Challenges

Factors contributing to poor Texas outcomes included insufficient clinical transition services payment, too few adult providers, poor understanding of transition to adulthood planning, and provider reluctance to initiate conversations with youth and families to prepare for adult-based care.

Opportunities

The STAR Kids Medicaid managed care program for CYSHCN requires service coordinators to actively engage youth and families in transition planning beginning at age 15. MCH requires CM contractors to initiate adult services transition planning with all youth beginning at age 12. MCH will continue working with educators to promote health care transition goal inclusion in school-based planning and expand strategic Texas partnerships with health care transition champions. MCH will actively engage and educate youth and young adults, families, clinicians, and professionals about transition through the TALC, statewide forums, and MCH contractors.

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. Nearly half (49%) did not feel a sense of belonging in their community. The same data showed that 77% of CYSHCN did not have access to inclusive after-school programs and 66% did not have access to inclusive preschool. Additionally, 26.9% of caregivers reported they needed respite care but were never able to receive it. The top 3 most common barriers to accessing respite care were lack of providers, finances, and not knowing about respite care. To improve these findings, MCH developed 6 State Action Plan strategies to increase the percentage of CYSHCN and their families who participate in social and recreational activities with families who have children with or without disabilities. Guided by the strategies, MCH implemented numerous projects to improve community inclusion.

In FY22, MCH distributed 3,217 "Communicating with and about People with Disabilities" brochures. The brochure offers helpful guidance about speaking with and about people with disabilities in a respectful, accurate, neutral, and objective way. MCH also distributed 5,715 "A Guide to Community Inclusion" brochures in English and Spanish. The brochure promotes the inclusion of CYSCHN and their families in all aspects of a community of their choosing without exclusion or judgement. MCH promoted and distributed printed and digital copies to families, caregivers, community members, and professionals.

MCH presented a CYSHCN program overview for the HHSC Office of Disability Prevention for Children's webinar series. The presentation covered the 3 CYSHCN performance measures with an emphasis on CYSHCN inclusion in health programming and community life and reached 507 attendees. Of the attendees responding to the post-webinar survey, 92% agreed or strongly agreed the presentation was informative and 94% agreed or strongly agreed they will personally or professionally use the information.

MCH was able to present, display information, and attend informational sessions at the in-person TxP2P statewide conference held in Austin. Eleven self-advocates, 105 families, and 37 professionals attended the conference.

In FY22, MCH developed social media content for Developmental Disabilities Awareness Month and National Family Caregiver Month. DSHS posted the content to Facebook, Twitter, and Instagram. The posts had 44,214 impressions (the number of times the content was displayed) and reached 17,040 viewers.

The 2020 Title V needs assessment findings identified a state priority need to implement health disparity strategies across all MCH populations. In FY22, MCH developed the CSHCN Technical Assistance project to build community-based organization capacity to provide FSCR services for CYSHCN and their families experiencing health disparities. MCH negotiated a 3-year contract with TXIFCW and this project work will begin in FY23.

MCH funded FSCR contractors to help CYSHCN and their families participate in community life and prevent crises even with the significant challenges of the pandemic. The FSCR contractors kept families updated on outdoor and virtual social activities, distributed free community event tickets, and offered virtual programming. These events helped families strengthen their sense of belonging, feel valued by their community, and connect with other families.

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

- Providing linkages to resources for essential needs such as housing and food;
- Providing smartphones and tablet computers so families could access telehealth and meet their children's educational needs;
- Offering parent self-care workshops and support groups;
- Offering SibShops to provide siblings peer support in a recreational setting; and
- Sponsoring community events to bring families together and increase their sense of belonging.

The FSCR and CM contractors conducted the following FY22 activities to strengthen families and advance inclusion.

Respite

FSCR contractors held virtual and socially distanced outdoor respite and recreational events. MCH funded FSCR contractors to offer respite for families. In FY22, 658 CYSHCN families received 19,163 hours of respite care.

Any Baby Can of Austin held a 3-day CYSHCN and sibling overnight camp that offered parent respite. Campers participated in arts and crafts, archery, swimming, horseback riding, and therapeutic groups. The camp staff encouraged CYSHCN to develop social connections with other children through fun, safe, and age-appropriate activities.

Family Education, Support, and Networking

TxP2P held its 16th Annual Statewide Parent Conference in person for the first time since 2019. The event featured 38 breakout sessions on mental

health, emergency preparedness, special education, parent leadership, medical transition, grief, Medicaid and Medicaid waivers, and caring for the caregiver. During the conference, TxP2P offered a SibShop, a YSHCN peer-to-peer conference, and childcare. Over 2 days, 153 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 also held South, East, and West Texas regional conferences and had 252 parents and 97 professionals attend. Sessions were held in English and Spanish and local vendors shared resources with families. TxP2P held weekly virtual parent support groups in English and Spanish connecting families across Texas to learn from each other. Self-advocates participated in the conversations, appreciated the opportunity to connect, and reported learning from what the parents had to say.

Recreational Activities and Initiatives

Based on the successful FY21 COL partnership with its parks and recreation department to create a multi-sensory room for CYSHCN and their families, the project expanded to 4 additional rooms at libraries across Laredo. In FY22, the city collaborated with Laredo Public Libraries to develop sensory rooms and host monthly community support group meetings, workshops, and inclusive library activities throughout the year. The room provides a communal space with sensory experiences designed to help CYSHCN feel calm, supported, and focused.

The Autism Services Program at Any Baby Can of San Antonio added social groups for children and youth on the spectrum to practice social skills in a safe place and for families to connect. During the fall event, the contractor gave parents and children a social narrative on how to trick-or-treat, invited families to practice trick-or-treating, and held a resource fair. At the winter event, families received social narratives on how to greet others and have a conversation. The contractor invited families to practice these skills at cookie decorating, pin the nose on Rudolph, and ornament decorating stations.

MCH represented DSHS as a Texas Council for Developmental Disabilities (TCDD) voting member. TCDD's mission is to create change so all people with disabilities are fully included 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. In FY22, quarterly meetings focused on state and federal policies and practices impacting people with disabilities and ways to address unmet needs in the disability population.

MCH served on the Project Development Committee and contributed programming ideas based on published research on negative physician bias towards people with disabilities and family-reported needs. In response, TCDD funded 4 projects to develop resources and training to improve clinician knowledge of the lived experiences of people with disabilities and the health care delivery system serving this population. Also, in response to MCH input, TCDD updated a fact sheet on extending health insurance to inform more families of actions needed to continue coverage over age 26.

MCH served on the Community Resources Coordination Group (CRCG) Statewide Workgroup. A total of 147 CRCGs cover 247 of Texas' 254 counties and are comprised of public and private agencies that help children, adults, and families who have complex multi-agency needs. MCH contractors and PHRs participated in local CRCG meetings to support families in or near crisis with vital service identification and access. MCH attended quarterly CRCG Statewide Workgroup meetings and served on the workgroup's subcommittee to address training, communication, and data collection. MCH also recruited PHR and community-based contractor case management staff to help establish CRCGs in unserved areas. MCH supported the following FY22 workgroup activities:

- An informational video creation and distribution to increase CRCG understanding and awareness;

- CRCG website redesign to make it more user-friendly for families seeking support; and
- Quarterly newsletter development and publication with agency partner updates, upcoming events, and resources to over 13,000 recipients.

MCH served on the Outdoor Learning Environment (OLE!) Texas leadership team. OLE! is a statewide initiative that promotes healthy, nature-based outdoor spaces at early childcare programs to encourage physical activity. The leadership team met quarterly to receive updates from local OLE! chapters on improving resources and building implementation capacity in their early childhood programs. MCH added an inclusion lens to the initiative by advocating for intentional outreach, effective communications, and policy changes.

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 improved access to community-based services and helped families navigate complex systems through parent networking, sibling support, training, and workshops. The FY22 data point for Objective 1 is 5,202, a 47.4% 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 trainings, workshops, and events that support CSHCN in their community. The FY22 data point for Objective 2 is 3,355, an increase of 88.8% from the FY17 baseline.

Challenges

The pandemic presented challenges for FSCR and CM contractors. Social media and virtual programming remained the most effective ways to reach families, though in-person events slowly returned. There is a respite care provider and inclusive childcare shortage statewide. Inflation made it difficult for families to cover basic needs such as housing, utilities, and groceries. With the increase in living costs, childcare and recreational activities are often unaffordable.

Opportunities

MCH uses DSHS social media channels to increase messaging to families. MCH will continue offering technical assistance to contractors in maximizing engagement and reach through technology. Community-based contractors will continue to seek respite and childcare providers. MCH will continue supporting contractors offering inclusive recreation to families.