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

According to the 2019-2020 National Survey of Children’s Health data, children and youth with special health care needs (CYSHCN) made up 17.4% of children younger than 18 in Texas. The nationwide percentage of CYSHCN in this age range is 19.4. The same data identified that 33.3% of Texas CYSHCN received care in a medical home, compared to 42.2% of CYSHCN nationwide. In the 2021 CYSHCN Caregiver Outreach Survey, respondents reported that 71.72% of caregivers organized their child’s care themselves and 68.82% did not receive professional care coordination. The same data showed that nearly half of respondents (49.5%) did not have a plan for a medical emergency disaster. Still, a large portion of families had not planned for multiple kinds of emergencies. To improve on these findings, the Maternal and Child Health (MCH) Section developed six strategies (that can be found in the State Action Plan) aimed at increasing the percentage of CYSHCN having a medical home. Guided by the strategies, MCH implemented numerous projects to improve medical home outcomes.

MCH facilitated the Medical Home Learning Collaborative (MHLC) quarterly meetings to increase knowledge and share best practices related to medical homes. Participants shared new academic publications and resources about care coordination, health disparities, benefit programs, and upcoming events. FY21 meetings featured presentations on 2020 Title V Needs Assessment findings, the state of primary care in Texas, caring for people with Down syndrome in the medical home, and Help Me Grow Texas (see the Child Health narrative). Attendees included: parents, social workers, case managers, providers, community organizations, and other interested partners. In post-call surveys, participants reported overall satisfaction with the meetings and those presentations were relevant to their work. Between meetings, MCH shared information with members on new resources, events, and trainings.

MCH staff developed the 2021 CYSHCN Caregiver and Young Adult Outreach Surveys to monitor Texas' ongoing progress toward meeting Title V Children with Special Health Care Needs (CSHCN) performance measures. MCH worked with stakeholders to disseminate English and Spanish survey versions electronically and in print. Staff executed multiple strategies to boost reach and responses by:

- Sending CSHCN Services Program clients a paper survey in the mail;
- Developing a survey outreach toolkit consisting of posters, email and social media language, and flyers for MCH contractors, DSHS Public Health Region (PHR) office staff, and other partners to distribute;
- Offering the option to request a paper survey; and
Publicizing the surveys through social media.

Survey questions related to medical home assessed respondents' experiences with accessing primary and specialty care, emergency preparedness, and care coordination. The surveys also incorporated questions related to family experiences during the pandemic, including access to care, vaccine hesitancy, and barriers to vaccination.

MCH distributed several resources to increase awareness and understanding of medical home among families and providers:

- What is a Medical Home: A Guide for Providers;
- Every Child Deserves a Medical Home: A Guide for Families; and

All materials were developed in English and Spanish by MCH and are available to download from the MCH website or order at no cost.

In 2018, MCH surveyed certified community health workers (CHWs) in Texas to assess their knowledge of services and supports available to families of CYSHCN. Results showed that CHWs were not informed about available resources or the unique needs and challenges of CYSHCN families. To expand CHW's capacity to assist families of CYSHCN, MCH developed an introductory training to increase knowledge and understanding of:

- Challenges and needs of CYSHCN and their families;
- Resources about health care funding options for CYSHCN in Texas; and
- Strategies to advance community inclusion of CYSHCN and their families.

CHWs will receive DSHS continuing education credits upon course completion, which MCH plans to record in FY22.

The MCH-funded CSHCN Services Program, administered by Texas Health and Human Services Commission (HHSC), provides eligible CYSHCN up to age 21 and people of any age with cystic fibrosis a health care benefit to help assist in access to care and improve overall well-being. The program focuses on family-centered, community-based services that honor and respect families’ cultural beliefs, traditions, and values. To be eligible for benefits, clients must live in Texas, have an income level at or below 200% of the federal poverty level, and have a medical condition that:

- Is expected to last at least one year;
- Limits one or more major life activities; and
- Requires a higher-level of health care.

Additionally, the program’s rules require that clients have physical symptoms. A developmental delay, or having a mental, behavioral or emotional condition alone, does not meet the eligibility criteria. In FY21 1,521 clients received a benefit, of which 1,442 did not have any other
health insurance coverage. A total of 265 CYSHCN remained on the waitlist. The program removed 682 clients from the waitlist during the year to receive benefits. MCH and HHSC met monthly to stay informed on program changes and explore opportunities for collaboration.

MCH funded the Texas Institute of Family and Child Wellbeing at the University of Texas School of Social Work (the institute) to develop a case management practice model to provide high-quality, family-centered, and culturally sensitive services for CYSHCN and their families. The three-year project, guided by the National Care Coordination Standards for CYSHCN and launched in FY20, consists of 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.

As part of Phase I, MCH and the institute released a literature review and needs assessment report of CYSHCN case management services in Texas with recommendations to inform and guide development of the practice model. In Phase II, the institute facilitated three regionally representative advisory groups with case management staff and both English and Spanish-speaking caregivers. The groups provided ongoing feedback throughout development of the practice model. Phase III will begin in spring 2022 following the completion of case manager training.

MCH awarded 22 contracts to 13 community-based organizations through a competitive application process in FY20. Family Support and Community Resources (FSCR) contractors assist CYSHCN and their families by providing services in response to local needs including respite, emergency planning, recreation and fitness programs, parent-to-parent networking, and crisis prevention. In FY21, FSCR services, available in all eight PHRs, covered 136 of Texas’ 254 counties. Case Management (CM) contractors work 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 PHR staff to provide case management services to families of CYSHCN to help find services that were available to families in all regions of Texas. CM contractors met quarterly with PHR staff to ensure there was no duplication of services and to strengthen relationships.

In FY21, CM contractors assisted 980 clients and PHR staff assisted 1,053 clients with comprehensive case management services, which provided:
- Current COVID-19 health protocols, credible resources, testing center locations, and vaccine clinic information;
- Linkages to health care coverage, primary care and specialty providers, therapies including Applied Behavior Analysis, medical
transportation, durable medical equipment providers, and social services;
• Referrals to foundations and other funding sources to pay for medications and critical medical needs;
• Education about healthy living, and physical and emotional well-being;
• Stress management workshops to learn ways to better handle the emotional challenges of raising CYSHCN; and
• Encouragement so parents felt empowered to advocate as the true experts on their child’s needs.

Described below are highlights of FSCR and CM contractor FY21 activities to support the medical home model.

Care Coordination

Texas Children’s Hospital’s CHOSeN clinic, a practice serving only CYSHCN and young adults with medical complexity, organized care for emergency room visits, hospital admissions, follow-up after discharge, and postponed surgeries because of the pandemic. Comprehensive care during hospitalizations provided swift follow-up, continuation of services, and new orders for supplies and medications were quickly filled. For parents exposed to COVID-19, staff facilitated quick access to testing and the transition of care to relatives while the primary caregivers were isolated. CHOSeN also held a COVID-19 vaccination clinic for its most medically fragile patients.

Cameron County Public Health, in partnership with local clinics and Federally Qualified Health Centers, coordinated services to help CYSHCN families attended appointments and received needed care. The contractor helped clinic nurses and social workers follow up with families to reschedule missed appointments and assess needs for medical transportation or a virtual visit.

Emergency Preparedness, Safety, and Disaster Response

CM and FSCR contractors helped 3,321 clients with emergency preparedness planning and aid in FY21. Assistance included developing or updating 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 needs during an emergency. Contractors also hosted trainings for police and fire department staff about effective ways to interact with people with disabilities.

Education and Resource Sharing with Medical Providers

Texas Parent to Parent (TxP2P), the state’s Family to Family Health Information Center and Family Voices affiliate, offered their Medical Education (MEd) program on a scaled-back level. The contractor created the program to give residents and medical students a deeper understanding of the daily challenges facing families of CYSHCN and expand the base of informed physicians. In FY21, the program suspended in-person visits
because of the pandemic and announced plans to launch virtual visits featuring videos of families at home. The communication section of the curriculum gave participants opportunities to practice interview skills and ask parents questions about difficult topics. Parents shared insights from first receiving their child’s diagnosis and ongoing struggles to navigate complex systems.”. A majority of the 43 residents who attended the training responded “agree” or “strongly agree” to the evaluation question “MEd has increased my knowledge about the needs of children with disabilities and their families.”

Any Baby Can of San Antonio announced a new collaboration between its Autism Services Program and the University of Texas Health Science Center at San Antonio to educate medical students about disabilities. The content will be incorporated into the annual curriculum and center on strategies to effectively work with individuals with autism and other developmental disabilities. Planning began in the spring of FY21 and the program will launch in the spring of FY22.

To reinforce yearly expectations, MCH conducted a two-day virtual training for FSCR and CM contractors that provided guidance, education, and technical assistance. The sessions included trainings about:

- Emergency preparedness conducted by The Center on Disability and Development at the Hazards Reduction and Recovery Center at Texas A&M University;
- Family empowerment conducted by a self-advocate with TXP2P;
- Health disparities and intersectionality’s for CYSHCN;
- Contract requirements; and
- Tips for improving outreach through virtual platforms and social media.

To evaluate the quality of services provided by FSCR and CM contractors, MCH developed two types of family experience surveys in FY20 that were distributed in FY21. The FSCR survey measures contractor responsiveness to family inquiries, respect for culture and traditions, quality of linkages to needed resources, facilitation of parent-to-parent connections, and support with helping families feel included in the community. The CM survey measures family satisfaction with service plan development, emergency preparedness planning, timeliness of case managers’ follow-up with families, and shared decision-making for their child. In FY21, staff sent aggregate survey data to contractors quarterly so they could be aware of their progress, increase response rates, and make improvements to program planning and service delivery. During the year, FSCR contractors distributed 4,687 surveys and CM contractors distributed 1,077 surveys (5,764 total). The return rate was 18% for FSCR and 14% for CM reflecting an improvement from the previous fiscal year with a 3.5% increase combined. Specific findings identified that most families received:

- Accessible, family-centered, comprehensive services (94%);
COVID-19 delayed MCH from sending contractors additional printed surveys to distribute to families. Contractors who no longer had paper surveys had to devise ways to distribute surveys via text, email, and Quick Response (QR) codes. Many families lacked access to the Internet and technology which affected the number of survey responses. MCH will work with contractors in FY22 to improve the survey response rate.

Texas participated as one of 10 state teams in the Health Resources and Services Administration (HRSA)-funded Children with Medical Complexity (CMC) Collaborative Improvement and Innovation Network (CoIIN) project designed to improve the quality of life for CMC and well-being of CMC families. The Children’s Comprehensive Care Clinic at Dell Children’s Medical Center (the Clinic), a dedicated practice serving only children with medical complexity, was the state’s site for innovation. Nearly 400 clinic patients were part of the project’s cohort. In addition to MCH and clinic staff, the state’s team included families of children seen at the clinic, TxP2P, practicing clinicians, Medicaid managed care organizations, health systems researchers, policy experts with the Dell Medical School at the University of Texas, Children’s Hospital Association of Texas, HHSC Medicaid division, and other key stakeholders. Members of the project’s family workgroup held leadership roles and were central to planning and implementing the project’s quality improvement initiatives. MCH actively contributed by providing public health expertise, organizing meetings, composing the project’s report to HRSA, and attending national webinars, meetings, and learning sessions.

Texas CMC CoIIN Team accomplishments and FY21 highlights centered on:

- Expanding the role of the project’s family workgroup and increasing membership to better represent the diversity of clinic families;
- Responding to the pandemic by expanding telemedicine and integrating specialists and other providers (e.g., home health) into visits;
- Pursuing funding to continue innovations. Efforts were successful and the team received a grant from a local nonprofit for a two-year pilot project; and
- Designing a family-driven pilot to test virtual, twice-yearly, “whole child” visits to streamline assessments, test an alternate payment model, and reduce disparities in access to care by empowering families as equal partners within the health care system.

The family workgroup participated in every level of design and developed new outcome measures for the pilot which focused on what truly matters to CMC and their families.

The state’s CMC CoIIN team participated in the Maternal and Child Health Bureau (MCHB)-funded National Care Coordination Academy designed to support state teams with tangible implementation and sustainability.
strategies and tools for care coordination. The initiative, led by Boston Children’s Hospital in partnership with the National Center for Care Coordination Technical Assistance and the National Center for Patient and Family-Centered Medical Home at the American Academy of Pediatrics, offered a unique learning community. This community met bimonthly to advance care coordination through targeted technical assistance and structured learning opportunities. HRSA awarded funds to continue the project for a second year. MCH participated in bimonthly Academy meetings to learn from the faculty and other state teams. The Texas team met monthly to strategize on development of the “whole child” visit and meaningful measures to evaluate outcomes.

The Mountain States Regional Genetics Network (MSRGN), a 7 state HRSA-funded collaborative, worked to assist people with heritable disorders and their families, particularly populations currently underserved, get access to genetic expertise and quality care. HRSA awarded the network funds to continue its work for a four-year grant cycle. The Texas MSRGN team included families, TxP2P staff, nurses, genetic counselors, public health professionals, the DSHS State Geneticist with the Newborn Screening Program, MCH staff, and other collaborators. Texas MSRGN team accomplishments and highlights during FY21 included:

- Expanding membership to include a genetics graduate student and a staff member with the University of Texas Center for Disabilities Studies who is also a parent of a child with a genetic disorder;
- Working to identify clinic champions to educate, equip, and empower pediatric and primary care providers to improve their ability to serve those impacted by pediatric genetic conditions; and
- Convening a subgroup to improve provider perceptions about disability and delivery of unexpected news so families gain hope in knowing that people with disabilities can lead rewarding, meaningful lives.

MCH promoted Texas Health Steps’ Online Provider Education (THSteps) modules on medical home. THSteps’ award-winning online program offers free continuing education courses for primary care providers and other health professionals. In FY21, MCH offered subject matter expertise for updates on the module “Building a Comprehensive and Effective Medical Home,” which teaches professionals how and why to create and sustain a medical home in their primary care practice.

In FY21, the Texas Primary Care Consortium Steering Committee included MCH staff, hospital systems representatives, state agencies, primary care practices, pharmaceutical companies, professional associations, and universities. Committee members worked together to address systemic issues in health care, such as disparities, high costs, and lack of access. The Consortium held its annual summit as a four-part virtual series because of COVID-19. Sessions aimed to help attendees pursue a growth-oriented, forward-looking vision of primary care in Texas.
The Policy Council for Children and Families worked to improve the coordination, quality, efficiency, and outcomes of services provided through the state’s health, education, and human services systems. MCH staff served on the council alongside family members of CYSHCN and representatives of community, faith, business, and other organizations. Legislation required the council to include at least one adolescent or young adult with a disability younger than age 26 receiving services from a Texas Health and Human Services agency. Additionally, family members must comprise most of the membership. In FY21, the council submitted a biennial report with recommendations to the Texas Legislature and HHSC leadership. The recommendations supported advancements in all CSHCN performance measures. The council received updates on ongoing and emerging issues, including the state’s policy flexibilities during the pandemic to monitor and respond to impact on CYSHCN and their families.

Performance Analysis

**Objective 1:** By 2021, 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).

**Objective 2:** By 2021, increase the percentage of providers of CYSHCN who are provided education and support on medical home by 5% above baseline (FY15 THSteps participant baseline = 313).

Increasing awareness and access to a medical home remained an MCH priority. The MHLC, CMC CoIIN, Texas Primary Care Consortium, and other initiatives continued to improve recognition and implementation of the medical home model. MCH surpassed its goal to “increase the percentage of providers of CYSHCN who are provided education and support on medical home.”

Challenges/ Opportunities –MCH staff capacity and turnover and the pandemic impacted collaboration with medical home initiatives statewide.

MCH will continue to identify opportunities through our partners and CYSHCN Outreach Survey results to strengthen education and support for families about receiving care within a medical home. MCH will continue strategizing to increase involvement of clinical stakeholders with varying strengths, interests, and expertise to expand supports for CYSHCN and their families. An opportunity exists to educate clinicians and other providers about supporting CYSHCN families within the medical home to expand capacity to provide comprehensive, coordinated care. Ongoing projects, such as the case manager and community health worker trainings, will allow MCH to target education to specific health care professionals about medical home implementation. The STAR Kids Medicaid managed care program for CYSHCN mandates requirements for improved care coordination. The CMC CoIIN project is working to reduce systemic inefficiencies and improving medical home supports for children with the greatest need. Statewide, focused effort on improving service coordination for children will lead to
improvements in care delivery and health outcomes for CYSHCN served in managed care.

In FY23, managed care organizations (MCOs) will take over providing case management services for STAR Medicaid clients from DSHS PHR case managers. DSHS will continue to provide case management to CYSHCN not enrolled in STAR Medicaid. MCH is exploring opportunities to collaborate with MCOs and train Medicaid-enrolled providers in case management for CSHCN.

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

According to the 2019-2020 National Survey of Children’s Health, 14.9% of CYSHCN in Texas ages 12 through 17 received the services necessary to transition to adult health care, compared to 22.5% nationwide. In the 2021 CYSHCN Caregiver Outreach Survey, 69.1% of caregivers with transition-aged youth ages 12 through 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 six strategies (which can be found in the State Action Plan) aimed at increasing the percentage of youth with special health care needs who receive the services necessary to transition to adult health care. Guided by the strategies, MCH implemented numerous projects to improve transition outcomes.

The MCH-led Transition to Adulthood Learning Collaborative (TALC) met quarterly in FY21 to bring together partners working to improve transition outcomes. Members included caregivers, self-advocates, case managers, providers, educators, staff with managed care and community organizations, academic centers, and others. Participants exchanged information about state and national transition initiatives, publications, and new resources. The virtual meetings featured presentations addressing health care transition, planning for a good life in the future, vocational rehabilitation services, and connecting with community providers during the pandemic. Respondents to post-meeting surveys reported overwhelming satisfaction with the meetings and noted how the presentations were relevant to their daily lives and work.

MCH staff presented on health care transition at virtual events during FY21. Presentations focused on incorporating health into transition planning at school, parents as partners in health care, and a person-centered tool for empowering youth. Staff also planned and moderated a panel of young adults at the TxP2P conference. The panelists offered insights on what did and did not work well during their transitions to adult-based care. A key takeaway was that, in the young adults’ view, transition does not end. The need to build knowledge and skills to successfully navigate the complexities
of health care is ongoing and messages implying otherwise can lead to feelings of failure.

MCH distributed resources to help families and providers learn about health care transition and understand the importance of active planning:

- "What is Health Care Transition," a guide for families; and
- "What is Transition," a guide for health care providers and other professionals.

The materials, developed by MCH in both English and Spanish, were available to download from the MCH website.

MCH developed the 2021 CYSHCN Caregiver and Young Adult Outreach Surveys to monitor Texas' ongoing progress toward meeting Title V CSHCN performance measures. Transition questions addressed whether the family or young adult had prepared for different aspects of transition, who helped families and young adult prepare for transition, and what services would help with transition planning. The surveys aimed to identify areas where families needed more transition-related support and where service delivery could be improved. Information about survey methodology is detailed in NPM 11.

MCH funded CM and FSCR contractors and PHR staff throughout Texas to help prepare CYSHCN and their families in all areas of transition. CM contractors assessed readiness for all clients over age 12. CM and FSCR provided 4,658 transition services for CYSHCN in FY21. PHR staff conducted 405 encounters with youth and young adults to provide transition resources. CYSHCN were eligible to receive multiple services during the fiscal year.

CM and FSCR contractors, and PHR staff assisted youth and young adults and their families to plan for adulthood by offering:

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

Described below are FY21 highlights of contractor activities to improve transition outcomes.

Health Care Transition Education
The Coalition of Health Services collaborated with a local organization to sponsor the virtual workshop “You and Your Body,” held in Spanish and English for transition-age young women with disabilities. Female family members and caregivers also attended to learn effective ways to continue sensitive conversations at home and the importance of teaching correct body part terminology. The young women identified people in their lives to reach out to for help and learned about privacy, breast cancer awareness, the human papillomavirus vaccine, and self-advocacy. Families discovered their children with disabilities had the same questions as their children without disabilities.

Families working with the University of Houston’s Families CAN program had questions and concerns as their young girls with disabilities approached puberty. The contractor offered two workshops in English and Spanish to educate families about ways to talk with youth about puberty. Families learned how to ask primary care providers for help with empowering youth to be more autonomous with their health needs.

The CHOSeN Clinic worked with youth and young adults with medical complexity who wanted to be as independent as possible and self-manage their care. Staff taught patients about their diagnoses, health insurance, and how to navigate the medical system and effectively communicate with medical teams, nursing agencies, and equipment companies. Starting at age 12, all youth received a health care transition readiness assessment for review at future visits. The clinic collaborated with the University of Texas’ Medical Legal Partnership to assist families with supported decision-making agreements, guardianship, and setting up special need’s trusts.

The Heart of Texas Independent Living Center educated area physicians about Medicaid and how families can add their child’s name to the Medicaid waiver lists. The contractor informed physicians about the state’s policy permitting single-case agreements which enable CYSHCN with Medicaid benefits to receive care from a non-Medicaid provider. As a result, CYSHCN were able to maintain relationships with existing providers and reduce their family’s out-of-pocket expenses.

**Transition to Adult Services**
TxP2P offered Pathways to Adulthood (PTA) workshops for families and professionals throughout Texas. The virtual format made it possible for those who would not have attended otherwise to participate. Sessions addressed health care, higher education, legal needs, finances, creative approaches to employment and housing, support networks, and more. Parents shared first-hand experiences to give insights to parents new to the planning process. A total of 191 parents and 58 professionals, including clinicians, social workers, teachers, and transition specialists attended the 16 workshops in FY21. Respondents to workshop evaluations reported benefiting from the trainings by learning about community resources and seeing examples of what is possible. The group setting, even in a virtual format, allowed parents
to exchange ideas and provided comfort to them knowing they are not alone on the transition journey. TxP2P also held its first Peer Parent Mentor trainings, one in English and one in Spanish, for the PTA program to build parent-to-parent mentoring support.

Paso del Norte Children’s Development Center hosted a transition conference for youth and parents to learn about higher education programs for young adults with intellectual and developmental disabilities and Texas Workforce Commission services. The contractor provided Spanish translation and closed captioning to make the event accessible to participants. The case manager encouraged youth and parents to have conversations with school counselors and vocational rehabilitation specialists to explore possibilities before making decisions.

Collaborating with School Teams
The Northeast Public Health District (NET Health) and TxP2P collaborated with a local school district to present the East Texas Parent Conference. A total of 49 parents, one self-advocate, and 15 professionals attended the virtual event. Interpreters allowed for Spanish-speaking parents to participate. Transition-focused breakout sessions addressed adult health care, alternatives to guardianship, person-centered planning, and education. NET Health provided childcare stipends so more parents could attend. Most evaluations indicated that parents found the information beneficial.

The Angelina County Community Health District staff met with school counselors and nurses at area high schools to offer education on health care transition planning. The contractor presented a virtual workshop to school staff and encouraged school teams to incorporate transitioning from pediatric to adult health care into the planning process.

MCH served on the Advisory Board and attended the 21st Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care hosted by the Baylor College of Medicine. The virtual conference addressed the critical need to expand the skills and knowledge of health care professionals to facilitate successful transitions from pediatric to adult providers. Presentations focused on topics including dentistry for adolescents and young adults with medical complexity, legal and employment issues, the role of nurses in transition planning, and both young adult and parent perspectives. TxP2P, with funding from MCH, provided 22 scholarships for youth and parents to attend. Additionally, MCH participated on the advisory board for the 22nd annual health care transition conference planned for the fall of 2022.

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 efforts in each other’s states to partner with school teams. Group members know from experience that transition specialists, teachers, and school nurses recognize the importance of addressing health in Individual Education Plans (IEPs) even though federal law does not
require schools to address it. In FY21, the group explored ways to engage other state Title V programs and planned next steps to increase impact.

MCH staff helped to revise the Texas Education Authority’s Texas Transition and Employment Guide by developing content for the health care transition chapter, offering resources, and giving input on other topic areas. The publication of the guide is planned for early FY22.

Performance Analysis

**Objective 1:** By 2020, 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).

**Objective 2:** By 2020, 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. (FY15 THSteps baseline = 1,084).

Efforts to advance understanding of changes in adult-based care 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 linkages to adult providers. MCH participated in state forums that offered opportunities to bring further awareness. MCH will work to actively engage and educate youth and young adults, families, clinicians, and professionals about transition through the TALC, statewide forums, and MCH contractors.

Challenges/ Opportunities - Factors contributing to poor outcomes in Texas included insufficient payment for transition services, too few adult providers, lack of understanding of the importance of planning, and provider reluctance to initiate conversations with youth and families to prepare for adult-based care. The STAR Kids Medicaid managed care program for CYSHCN, launched in early FY17, requires service coordinators to actively engage youth and families in transition planning, including to adult health care, beginning at age 15. Requirements for CM contractors to initiate planning with all youth beginning at age 12 helps with active preparation for transitioning to adult services. MCH continues working with educators to promote the inclusion of health care transition goals in school-based planning and expand strategic partnerships in Texas with health care transition champions.

**SPM 11: 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 nearly half (49%) of respondents did not feel a sense of belonging in their community. The same data showed that 84% of CYSHCN did not have access to inclusive day care or after-school programs, and over 66.2% did not have access to inclusive preschool. Additionally, 76% of respondents reported needing respite care but only 6.5% had access to receiving the service whenever they needed it. The top three most common barriers to accessing respite care were finances, lack of providers, and not knowing about respite care. To improve these findings, MCH developed six strategies (which can be found in the State Action Plan) aimed at increasing 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.

Findings from the 2020 Title V Needs Assessment identified health disparities as a priority need. In response, MCH developed the Project to Address Health Disparities in FY21 and announced plans to contract with an entity to provide technical assistance to community-based organizations serving families experiencing health disparities. The contracted entity will provide assistance for organizations to build their capacity to provide culturally appropriate family support and community resource services to CYSHCN and their families.

MCH participated in workshops and discussions about reducing health disparities to increase staff knowledge and strategize about ways to apply learnings to current and future initiatives. MCH introduced the Health Equity Learning Lab, a forum for staff to approach difficult topics in a safe and supportive environment. MCH applied for and was awarded technical assistance through HRSA to partner with the Michigan Public Health Institute and participate in the ADJUST Health Equity & Social Justice workshops. MCH staff feedback indicated that participants found the sessions informative, enlightening, and worthwhile.

MCH surveyed all unit-level programs to assess practices, barriers encountered, and quality of engagement with MCH populations. Findings identified that 11 of 19 programs connected with families through focus groups, workshops, newsletters, and coalition partnerships. Several programs incorporated family input into improvement efforts. Additional findings from the MCH survey showed that the pandemic was a significant barrier to engaging with families and identified the need for clear guidance and standardized policies to improve the quality of family engagement.

MCH staff developed the 2021 CYSHCN Caregiver and Young Adult Outreach Surveys to monitor Texas’ ongoing progress toward meeting Title V CSHCN performance measures. Survey questions addressed community inclusion, participation in social and recreational activities, and access to respite, child care, and family support services. MCH added questions specific to the
pandemic to assess family experience with isolation and loneliness both before and during the pandemic, added stress, and frequency of online connections with friends and family. Findings will identify gaps in inclusive services, areas for service delivery improvement, and the pandemic’s impact on the mental health and emotional well-being of CYSHCN and their caregivers. Information on survey methodology can be found in NPM 11.

MCH created “Communicating with and about People with Disabilities” in FY21 to offer helpful guidance about speaking with and about people with disabilities in a way that is respectful, accurate, neutral, and objective. The handout was promoted widely and distributed in both paper and electronic formats.

MCH-funded FSCR contractors to help CYSHCN and their families participate in community life and prevent crises even with the significant challenges brought by the pandemic. The FSCR contractors kept families up to date on outdoor and virtual social activities, distributed free tickets to community events, and offered virtual programming to minimize isolation and loneliness for CYSHCN, their parents, and siblings. These events helped families connect with each other, strengthen their sense of belonging, and feel valued by their community. MCH required CM and FSCR contractors to adopt and conduct inclusive practices. Contractors accomplished this by reaching out to at least two community organizations, who focused on serving minority populations each quarter.

Because of COVID-19, FSCR and CM contractors canceled activities, which resulted in unused funds. Guidance from DSHS allowed contractors to divert unspent funds directly to families impacted by the pandemic. These one-time emergency funds made it possible for families in crisis to pay for food, clothing, housing, utilities, furniture, transportation, phone, laundry, supplies for the home, medical supplies, and other basic needs. Families lost their primary caregiver to COVID-19 while others were hospitalized which led to increased requests for emergency funds.

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

- Assisting families in accessing housing, connecting with local food banks, accessing personal protective equipment, and providing linkages to access other essential needs;
- Providing smartphones and tablet computers so families could access telehealth and meet their children’s educational needs;
- Offering self-care workshops and support groups for parents, CYSHCN, and siblings; and
- Sponsoring outdoor community events to bring families together and increase their sense of belonging.

Described below are FY21 highlights of FSCR and CM contractor activities to strengthen families and advance inclusion.

Respite
FSCR contractors held numerous respite and recreational events virtually or in outdoor venues with social distancing precautions in place. MCH funded FSCR contractors to offer in-home respite for families. A total of 558 CYSHCN families received a total of 21,115 hours of respite care.

Any Baby Can of Austin hosted a virtual workshop for caregivers focused on increasing self-care and managing stress. A program for CYSHCN and their siblings was held simultaneously and included activities to help better manage stress following the winter storm and the impact of the pandemic. The event, held in English and Spanish, also provided American Sign Language interpretation. The contractor held its annual inclusive camp virtually for CYSHCN, children with cancer, and their siblings without disabilities, and children who lost a sibling because of a health care condition.

Family Education, Support, and Networking
TxP2P held its Statewide Parent Conference virtually for the second year. The event featured 27 breakout sessions with eight offering Spanish translation. Three additional sessions were conducted in Spanish. Topics included parent empowerment and leadership, personal support networks, early childhood intervention, mental health, emergency preparedness, Medicaid waivers and more. Evaluations and chat comments showed that attendees found the sessions informative and worthwhile. A total of 217 participants including parents, self-advocates, and professionals attended over both days. TxP2P also presented “Giving Thanks with a Grateful Heart” and weekly parent support groups throughout the year, which brought families together from throughout Texas to learn from each other. Sessions were held in English and Spanish. Self-advocates participated in the conversations, appreciated the opportunity to connect, and reported learning from what the parents had to say.

Any Baby Can of San Antonio expanded its sibling support group which allowed participants to discuss their feelings towards their siblings and how emotions can be overwhelming and how to learn coping skills. Providing a safe space for siblings to openly share with others experiencing similar challenges helped reduce feelings of loneliness and isolation.

Recreational Activities and Initiatives
The City of Laredo partnered with its Parks and Recreation department to advance meaningful inclusion for CYSHCN and their families. The partners created a multi-sensory room to expand opportunities for CYSHCN to fully participate in community life. The room, designed to stimulate the multi-sensory pathways of touch, taste, sight, sound, smell, and movement, aimed to produce either a calming effect or stimulate passive individuals. Parents were encouraged to use the room with their CYSHCN to improve motor development, language skills, relaxation techniques, and increase socialization. The city’s staff also completed the four-day SibShop facilitator training to offer siblings of CYSHCN opportunities for peer support and education in a fun, recreational environment. Energized by their motto “A
healthy caregiver will give healthy caregiving,” the city evaluated primary caregivers for burnout and offered education about emotional and physical health. The city connected parents to free health care, including mental health services, for themselves. These efforts supported caregiver well-being to help CYSHCN to continue growing up at home in their community.

MCH represented DSHS as voting members of the Texas Council for Developmental Disabilities. The council’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. FY21 quarterly meetings focused on state and federal policies and practices impacting people with disabilities and ways to address unmet needs within the disability population. MCH partnered with the council and Texas A&M AgriLife Extension to develop a series of early childhood workshops. The series, designed to provide early childhood educators with knowledge and resources to implement inclusive practices in preschool classrooms, will consist of 8 weekly online courses and webinars. The council and AgriLife Extension plan to issue credentials for completion of the workshop series when it is launched in FY22.

MCH staff served on the Community Resources Coordination Group (CRCG) Statewide Workgroup. Located in 247 of 254 Texas counties, CRCGs comprise public and private agencies that partner with children, adults, and families who have complex, multi-agency needs. MCH contractors and PHR staff participated in local CRCG meetings to support families in or near crisis in identifying and accessing vital services. MCH attended CRCG Statewide Workgroup quarterly meetings to help advance interagency coordination of activities. MCH staff also served on the workgroup’s subcommittee to address training, communication, and data collection. Highlights of FY21 activities included:

- Establishing new CRCGs in several counties that were missing a CRCG;
- Hosting the CRCG and Texas System of Care Conference attended by 437 people. MCH served on the planning committee; and
- Hosting a webinar “Engaging with Youth of Color” attended by over 250 people.

MCH served on the leadership team for the Outdoor Learning Environment (OLE!) Texas, a statewide initiative that promotes healthful, nature-based outdoor spaces at early child care programs to encourage physical activity. OLE! Met quarterly to plan outreach activities and received updates from local chapters working to improve resources and build capacity to implement OLE! In their early childhood programs. MCH added an inclusive lens to the initiative by advocating for the inclusion of CYSHCN through intentional outreach, effective communications, and policy changes.

Performance Analysis
Objective 1: By 2020, increase the percentage of CYSHCN and their families who are provided education and support on utilization of Family Supports and Community Resources by 2%. (FY17 FSCR services to families’ baseline = 3,529).

Objective 2: By 2020, 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 services for providers’ baseline = 1,777).

MCH staff and contractors continued efforts to improve access to community-based services and help families navigate complex systems through parent networking, sibling support, and educational trainings and workshops.

Challenges/ Opportunities
The pandemic again presented challenges for FSCR and CM contractors. In-person services and events only resumed briefly because of the spread of the Delta variant of COVID-19. At the same time, the increase in virtual programming offered opportunities to connect with families in rural areas or who otherwise would not participate. Social media and virtual programming remained the most effective ways to reach families. MCH utilized DSHS’ social media channels to increase messaging to families. MCH staff provided technical assistance to contractors on leveraging technology to maximize engagement and reach the communities they serve.