

State Action Plan Table

State Action Plan Table (Georgia) - Children with Special Health Care Needs - Entry 1

Priority Need

Improve systems of care for children and youth with special health care needs

NPM

Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care

Objectives

9.1. By 2020, outreach and awareness activities on health care transition will reach 2,500 community stakeholders, youth and families.

9.2. By 2020, 500 health professionals will receive training and educational opportunities on health care transition.

9.3. By 2020, improve the standards of care for youth and young adults by implementing evidence-based health care transition protocols within 40 public and private practice settings.

Strategies

9.1.a. Develop health care transition materials for stakeholders, youth and families

9.1.b. Develop a Health Care Transition Resource Portal

9.1.c. Provide health care transition presentations to community stakeholders

9.1.d. Establish and maintain community partnerships to facilitate the distribution of health care transition resources and materials

9.1.e. Provide 20 health care transition planning workshops for families and youth

9.2.a. Provide an online continuing education module on the six core elements of health care transition targeting a minimum of 10% of public health nurse workforce

9.2.b. Provide continuing education opportunities on the six core elements of health care transition for medical and nursing students, pediatric and adult providers

9.2.c. Provide an annual stakeholder meeting with continuing medical education credit for pediatric and adult providers to discuss evidence based practices, medical home and transition and coordination of care across pediatric and adult systems

9.3.a. Establish an advisory group to include youth, families, and providers to support practice improvement efforts for health care transition

9.3.b. Incorporate the use of transition readiness assessments and planning tools within the 18 district Children's Medical Services (CMS) programs

9.3.c. Assess family and youth satisfaction of the health care transition services and supports upon transitioning out of the program

9.3.d. Partner with pediatric and adult medical providers to provide guidance and support in the development and implementation of a health care transition policy within their practice

ESMs

Status

ESM 12.1 - 9.1.1 Number of youth, families and professionals trained on health care transition

Active

ESM 12.2 - 9.3.1. Number of pediatric and adult medical providers who have a health care transition policy within their practice

Active

NOMs

NOM 17.2 - Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system

NOM 19 - Percent of children in excellent or very good health

State Action Plan Table (Georgia) - Children with Special Health Care Needs - Entry 2

Priority Need

Improve access to specialty care for CSHCN

SPM

By 2020, increase the rate of children and youth with special health care needs that have accessed their specialty health care visit through a telehealth clinic from 1.3 (per 1000 CYSHCN) to 2.0.

Objectives

10.1. By 2020, increase outreach and awareness activities on telehealth to reach 500 health care professionals and families.

10.2. By 2020, improve the telehealth infrastructure required to support children and youth with special health care needs access to medical care by increasing children's medical services telemedicine clinics provided from 96 to 175.

10.3. By 2020, increase the types of pediatric specialty practices participating in the DPH telehealth network from 2 to 6.

Strategies

10.1.a. Provide comprehensive telehealth information to providers

10.1.b. Facilitate efforts to educate families about telehealth as an option for care

10.2.a. Assess the infrastructure needs of the Children's Medical Services (CMS) Program telehealth clinics

10.2.b. Collaborate with the Department's Telehealth team and Waycross Health District to expand telemedicine sites

10.2.c. Expand the telemedicine provider network

10.2.d. Establish a telehealth stakeholder workgroup for CSHCN

10.2.e. Collaborate with the Department's EPI team to conduct a needs assessment and to develop a program evaluation plan

10.3.a. Utilize telehealth to improve care coordination efforts for CSHCN

10.3.b Utilize telehealth to improve access to audiological and speech therapy services for CSHCN

10.3.c Utilize telehealth to improve access to services for children and youth with sickle cell disease

Children with Special Health Care Needs - Plan for the Application Year

Plans for Coming Year

Priority Need: Improve Systems of Care for CYSHCN

NPM 12: Transition to adult care for all children

Improving system of care for CYSHCN is a priority need that will be addressed by using outreach and awareness activities on health care transition, increasing training and educational opportunities for health care professionals, and implementing transitional protocols within public and private practice settings to standardize the care for youth and young adults. Efforts for next year will focus on streamlining and evaluating the transition planning process for young adults enrolled into the Children Medical Services (CMS) program and using evidence-based transition readiness and planning tools. CMS will continue to provide guidance, support and training opportunities to pediatric providers in establishing transition policies. As well as to engage with existing DPH partners to assist with reaching adult providers, nursing students and academic institutions so that we may emphasize the importance of health care transition.

SPM 02: Improve access to specialty care for CSHCN

In the coming year, CMS continues to expand clinical services throughout Georgia and to enhance telemedicine services by collaborating with medical partners, community stakeholders and families. Efforts for next year will include continued engagement with the GaLEND and Center of Excellence in MCH Education, Science, and Practice at Emory Rollins School of Public Health programs to ensure children and youth with special health care needs have access to a comprehensive and accessible system of care. With the recent approval of Medicaid reimbursement for speech therapy services via telemedicine, the CMS program will partner with the Part C Early Intervention, Babies Can't Wait, program to explore tele-interventions for infant's birth to three years of age. The CMS program will also work with the MCH evaluation team and Telehealth Department to strengthen mechanisms to monitor access to and satisfaction of specialty care services.

Babies Can't Wait (BCW)

In the coming year, the Babies Can't Wait Program will continue to serve children birth to three with developmental delay and category 1 chronic conditions. BCW continues to focus on improving provider service to enrolled children and will offer a variety of training opportunities. BCW will partner with a variety of professional associations such as the Physical Therapy Association of Georgia to of continuing education credits for BCW offered training. In the coming year, BCW will also review and revise Georgia's category 1 list. This list currently includes microcephaly, hydromicrocephaly, and micrencephalon; all zika related conditions. BCW will determine if "confirmed zika infection" or other zika related conditions should be added to the category 1 list.

Autism

In the upcoming year, The Autism Initiative will continue to expand Georgia's capacity for early diagnosis by training a new cohort of licensed psychologist to administer the ADOS-2 diagnostic instrument. The goal is to have trained 90 licensed psychologists across Georgia and decrease families wait time in receiving a comprehensive evaluation. In collaboration with The Emory Autism Center (EAC), the Autism Initiative will pilot the use of Autism Specialty Clinics by making a request for applications to existing Georgia Autism Assessment Collaborative (GAAC) professionals. To improve access to care for children and youth with ASD, the Autism Initiative and EAC will develop a supervision and training program for professionals seeking to obtain Board Certified Behavioral Analysis (BCBA) credentials. While enrolled in the BCBA Training and Supervision Program, trainees will provide low-to-no cost behavioral intervention services to 200-260 children with ASD.

The Georgia Autism Initiative will continue to focus on The *Autism Navigator* will be modified to address skills related to early identification and screening in a 7 hour, self-paced, web-based course. The Autism Initiative will target a broader range of professionals to include Children First Coordinators and Home Visitors. At least 5 health districts will be identified to establish *Autism Navigator* learning communities with tiered training mechanisms for reinforcement of workforce development. The Autism Initiative plans of offer autism specific screening to children enrolled in the Part C Early Intervention program, Babies Can't Wait, at the 18 month and 24 month intervals recommended by the American Academy of Pediatrics.

Children with Special Health Care Needs - Annual Report

Reporting Year Oct 2015-Sept 2016

Priority Need: Improve Systems of Care for CYSHCN

NPM 12: Transition to adult care for all children

Health Care Transition is a National Performance Measure for the State of Georgia. The goal is to increase the percentage of youth and young adults that successfully transition to adult health care services from 33.9% to 39% during the next five years. Health care professionals, youth and families each have essential roles to play in improving a youth or young adult's transition from pediatric to adult health care. Positive transitions begin when youth and families are prepared for change and when pediatricians and adult primary care professionals have access to tools and concrete methods to address barriers and improve care for youth and young adults. The areas of focus include:

- Training opportunities for health care professionals
- Outreach and awareness activities geared towards youth, families and community stakeholders
- Implementation of health care transition protocols and standards in public and private health care settings

The focus of the Children and Youth with Special Healthcare Needs' (CYSHCN) program, Children's Medical Services (CMS), is to provide program development, leadership, guidance, and resources to Georgia's 18 Health Districts in the development and provision of a comprehensive, integrated, and coordinated system of services for children and youth with special needs, birth to age 21 and their families. Georgia's CMS Program is the leading program to support the transition of CYSHCN into the adult health care system.

Children's Medical Services

The Children Medical Services (CMS) Program partners with the community, health care providers, and local resources to coordinate the care for CYSHCN and their families, and strengthen health care transition services. Children and youth (ages 0-20) with eligible chronic medical conditions, and family income less than 247% of the federal poverty level are served by CMS.

Continuity in medical care for CYSHCN is critical to achieving optimal outcomes for these children and preventing death. CMS serves as the payer of last resort for health care and medical expenses for families that do not qualify for the State's Medicaid, SCHIP, or, are without insurance during the time of enrollment. In addition to filling in the gap with health care coverage, CMS will also support CYSHCN and their families by coordinating appointments, identifying resources, assisting with social support such as transportation and support groups with other families. Helping CYSHCN and their families feel confident about managing their health care needs and navigating through complex social issues is a very important goal for CMS.

CMS Care Coordinators assess eligibility for the State's Medicaid and SCHIP programs and assist with the applications if clients do not have insurance or express a burden in maintaining health care. For special cases, CMS Care Coordinators requests additional assistance from the Georgia Department of Community Health that administers the Medicaid and SCHIP Programs. In State Fiscal Year (SFY) 16 (June 2015-July 2016); 9,329 children and youth received care coordination services from the CMS program.

During the reporting year, CMS collaborated with the Care Management Organization (CMO), Amerigroup Georgia Families 360, program to ensure better coordination of services for children and youth in foster care, in the adoption process and under the care of juvenile justice. The Association of Maternal and Child Health Programs' (AMCHP) Strengthening Your System of Care for CYSHCN Action Learning Collaborative accepted Georgia's application to focus on this collaborative work with Amerigroup.

The MCH Section partners with Parent to Parent of Georgia (P2P) to implement the Parent Partner Project. Parent Partners are parents of a child or youth who has a special health care need and provide support to other parents who have children with special health care needs as well. The Parent Partners are paid as part-time employees of P2P and support local district child health programs and private pediatric physician practices. Parent Partners provide information & resources, emotional support, and coordinate free training opportunities for parents served at their site.

Since the initiation of the program, there have been a six (6) Parent Partners trained and supporting families with children and youth with special health care needs. Parent Partners have served 1,400 families and coordinated 142 Parent Matches. Parent Matches is a P2P service, in which a parent of a child with a special health care need or disability is matched with a Supporting Parent with similar situation and challenges. The Supporting Parent is knowledgeable and able to provide one-on-one emotional support and guidance.

The most frequent requests for assistance that come from parents include; community resources, early childhood services, education, parent and family support, and healthcare. The Parent Partners have coordinated 20 trainings for parents and professionals in the community. P2P also maintains the Statewide Central Directory database funded by the MCH Section. The Directory allows users to search for information and referral resources or families of children ages birth to twenty-six (26) with developmental delays, disabilities and chronic health care conditions.

The CMS program provides and/or arranges for comprehensive physical evaluations, diagnostic tests, inpatient/outpatient hospitalization, medications and other medical treatments, post-op therapy, durable medical equipment, hearing aids related to the child's eligible condition, and genetic counseling. For youth ages 16 and older, the program staff guides and coordinates the transition process from pediatric to adult health care. Pediatric specialty care clinics for children and youth living in rural counties in Georgia are offered where pediatric medical specialist's services are limited. In SFY16, 97% of children and youth enrolled were linked to a primary health care provider.

Approximately 1,027 CMS program participants, ages 16 and older, and their families received transition planning, support and education by care coordinators to facilitate successful healthcare transition in SFY 2016. The care coordinator's role in the transition process is one of planner, facilitator and support to the adolescent and family. The coordinator assists with transitioning the youth from pediatric care to physicians trained in adult medicine, ensuring that families and youth understand the health care systems available and learn to navigate services for adults with disability.

Transition Projects

During the reporting year, the CMS Program partnered with stakeholders to improve Georgia's systems of care and reinforce positive transitions for CYSHCN.

The CMS program partnered with the Adult Disability Medical Home (ADMH) to implement a quality improvement initiative named "Step Up to Health Care Transition" to enhance transition services for patients 12 years of age and older with intellectual and developmental disabilities. Step Up to Health Care Transition uses the Six Core Elements of Health Care Transition as a framework. ADMH is housed within a family physician practice and transition clinics are supported by several disciplines, which includes: a dietician, behavioral analyst, clinical social worker, and family/patient advocate. Three transition clinics are conducted per month, with 5-7 patients seen at each clinic.

ADMH's Medical Directors serve as Physician Champions for health care transition and are asked to support many of the activities coordinated by the CMS program, which includes educating health care providers via webinars and conference lectures.

Dr. Leila Jerome Clay, Director of Sickle Cell Disease Transition with Augusta University, continues to serve as a Physician Champion for the CMS program by participating in conference lectures and providing direct services to patients (13 to 18 years of age) transitioning from pediatric to adult hematology care. Patients are seen in clinic in Augusta, as well as, in outreach clinics in Dublin, Valdosta, and Waycross. An annual "Stomp Out Sickle Cell" 5K Run/Walk hosted by the Comprehensive Sickle Cell Program and Sickle Cell Transition Program, attracts more than 150 community members annually, and provides support for transition related patient activities.

Health care transition training opportunities are made available for health care professionals and community stakeholders.

Eighty-three public health nursing staff received continuing education credits for the online "Health Care Transition for Adolescents and Young Adults" training offered by Got Transition. Also, the CMS program utilized telehealth technology and hosted the live broadcast of the 17th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care for public health district staff and community partners. Seventy-two participants received continuing education credits. In partnership with the Georgia Chapter of American Academy of Pediatrics and Georgia Academy of Family Physicians lecture presentations on health care transition are offered during their annual and summer conferences.

CMS partners with the Coaching and Comprehensive Health Supports (COACHES) Program, a federally-funded pilot project that seeks to improve the health and transition outcomes for youth aging out of foster care in Georgia, to increase client knowledge and skills related to health care navigation. The COACHES Program is delivered through a public-private partnership between Families First and Amerigroup Georgia (an HMO that manages health services for youth in foster care) and the Georgia Department of Family and Children Services. COACHES employs the DPH *Taking Charge of My Health Care* booklet as a tool to support client education on healthcare navigation. Approximately 70, youth in foster care ages 17-21, who participate in the voluntary COACHES Program have received the booklet as a part of their coaching skills plan tools. Additionally, COACHES uses the material to train staff who provide one-on-one health and social services coaching services to clients, to assist program Coaches in offering strategies to the youth that they serve, impacting approximately 100 youth.

Based on a survey of program clients across 10 priority areas youth are increasing their skill in navigating health services for themselves. Data show that youth are making their own medical appointments, accessing their Amerigroup Care Coordinators for assistance and, accessing reproductive health care through their Amerigroup funded insurance. Finally, COACHES participants are showing reductions in healthcare spending related to in-patient behavioral health hospitalizations.

Community Outreach

MCH Section Child Health Programs within local public health departments host or participate in a variety of outreach events to build relationships with community partners, increase the number of referrals for child health programs, and inform clients of community resources. Some of the events include the SoopaFitt Health Expo and Street Festival in the LaGrange district providing medical screenings, flu shots, kid's workshops and Bounce House for kids. In the Clayton district, program staff participated in International Day hosted by the local Head Start program. The event provided medical screenings and children had the opportunity to dress up in costumes and take part in a parade. Nurses in the CMS program may also provide Asthma Education to school nurses and the Valdosta district hosts an annual SUPERPUFF Community Asthma Day Camp where asthma self-management education is provided via fun games (Asthma Monopoly, Asthma Jeopardy, Trigger Pictionary and Bronchial Tube Relay).

SPM 02: Improve access to specialty care for CYSNCH

The Children's Medical Services (CMS) Program partners with community, health care providers, and local resources to coordinate the care for CYSNCH and their families. To ensure that children and youth served in rural communities receive appropriate and needed specialty medical services, CMS offers specialty clinics in nine (9) local district programs, which include telemedicine services. CMS coordinates with more than thirty specialty providers for clinical services. During a twelve-month period, approximately 350 clinics are offered, 96 of those provided via telemedicine, and 3,800 children and youth served. Specialty clinics offered include:

- Endocrinology
- Nephrology
- Cardiology
- Chronic Lung
- Genetics
- Hematology
- Orthopedic
- Hearing
- Neurology
- Cystic Fibrosis

Other Programs

Early Intervention Services

Babies Can't Wait (BCW), also known as Part C, is an early intervention service to provide a coordinated, comprehensive and integrated system of service for infants and toddlers with special needs, birth to age 3, and their families. This program provides early identification and screening of children with developmental delays and chronic health conditions by using a multidisciplinary evaluation and assessment in order to determine the scope of services needed. BCW will then coordinate services to assist the family in developing a plan to improve the developmental potential of infants and toddlers with these health conditions.

Early intervention also allows for support and resources to be built to assist family members and caretakers to enhance children's learning and development throughout everyday learning opportunities.

BCW has served Georgia's children and families since 1987. According to Part C of the Individuals with Disability Education Act Amendment of 1997, early intervention services must be provided in natural environments, including home and community settings in which children without disabilities participate.

Georgia Autism Initiative

Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication, and behavioral challenges. ASD affects 1 in 64 children in Georgia. According to the National Center on Birth Defects and

Developmental Disabilities, Georgia children can be diagnosed as early as 2 years old and on average of 3 years and 9 months old.

DPH aims to help children and families with ASD and other related disorder through projects within the DPH Autism Initiative. The goal is to improve early identification, screening, diagnosis, early intervention and family support for Georgia children suspected of having, or diagnosed with ASD. For one of the projects, Georgia DPH partnered with Emory Autism Center to review, pilot the use of, and modify existing transition materials for individuals with ASD, caregivers/parents and healthcare providers. Based on the review of the materials and staff experience in working with adolescents with ASD and their families, supplemental materials were created to enhance ASD specificity.

Current Year Oct 2016-2017

NPM 12: Transition to Adult Care for All Children

The CMS program continues to engage various partners to improve the successful transition for youth and young adults from pediatric to adult care. In partnership with the Georgia Chapter of the American Academy of Pediatrics, the *Transitioning Adolescents with Special Needs from Pediatrics to Adult Primary Care Conference* was held in March, 2017. This conference was designed to help family physicians, internists, OB/GYNs, pediatricians and clinical healthcare professionals to address issues surrounding transitioning youth with special health care needs from pediatric to adult care. Continuing medical education credits were provided with twenty-six (26) participants in attendance. How to prepare a Transition of Care Policy for your practice was the theme of the seminar with practical applications from Health Care Transition Physician Champions, hospital systems, health plans and private providers. The CMS program continues to also partner with the Georgia Academy of Family Physicians to support health care transition activities, which include lecture presentation at their Fall and Summer meetings as well as live webinars. Both medical societies have updated their websites to include health care transition information, resources and links to the Got Transition website.

SPM: Improve access to specialty care for CYSN/CN

In the current year, CMS continues to expand clinical services to other areas of Georgia and enhance telemedicine services by leveraging existing partnerships with the medical community. During SFY15, there were only two (2) local district (Waycross and Valdosta) programs that offered telemedicine services for neurology, nephrology, pulmonology and endocrinology. In coordination with the Department's Telehealth team, the CMS program expanded telemedicine services to five (5) local district (Valdosta, Albany, Athens, Columbus, and Waycross) programs for patients needing sickle cell and genetic care. Additional efforts to support neurology and endocrinology for telemedicine services are underway, as well as the installation of equipment to support a telemedicine clinic in the Gainesville health district

CMS continues to research the best ways to allocate specialty care and telemedicine resources to expand their services and improve access to care for CYSN/CN. Thus, the CMS program partnered with the HRSA-sponsored Center of Excellence in MCH Education, Science, and Practice at Emory Rollins School of Public Health to establish a model to support the program in collecting and analyzing data that leads to improvements in the overall quality, access and continuity of care for children and youth with special health care needs. Core themes in the model include understanding the following:

1. Prevalence of disease in target population
2. Geographic access from patients to medical services
3. Financial access to medical services
4. Access to quality medical services

The model specifically looked at Critical Congenital Heart Defects (CCHD), and provided preliminary data that cardiology services are most needed in two (2) local districts (Dublin and Waycross) based upon the travel burden of children with CCHD (Age 0-20).

To assist with educating families about telemedicine as an option for care, the CMS program partnered with the Georgia Leadership Education in Neurodevelopmental Disabilities (GaLEND) Program and Early Hearing Detection and Intervention (EDHI) Program to help with developing strategies on structuring a family-centered and culturally-competent tele-audiology clinic for children with hearing loss. The GaLEND cohort interviewed key stakeholders, reviewed communication and evaluation materials and provided recommendations for the tele-audiology clinic flow and follow-up care.

Other Programs

Early Intervention Services

In the current year, the BCW program completed the Annual Performance Reporting (APR) and submitted it to OSEP February 2017.

The five State Systemic Improvement Plan (SSIP) districts identified two Master Cadres who were trained in the Pyramid model – Family Coaching and PIWI. These Master Cadres have worked side by side with our partners at Georgia State University to roll out the PIWI training to all non-licensed providers within their districts. As of June 2017, Gwinnett had one training left to complete and Coastal had four trainings. During the reporting year, the BCW program began working on the Family Coaching training, that will be rolled out to the same group of Providers through webinars or face to face trainings.

BCW also assessed the Strengths, Weakness, Opportunities and Threats (SWOT analysis) of the program. The SWOT analysis was conducted by a staff in 27 “hotspot” locations. Results will help BCW managers identify areas of improvement.

The BCW Program is also working closely with Parent 2 Parent and the Parent as Partners program. BCW recently implemented a parent satisfaction assessment survey and began collecting survey results.

Georgia Autism Initiative

In the current year, the Autism Initiative continues to expand Georgia’s capacity for early diagnosis by training psychologists to administer the Autism Diagnostic Observation Schedule, Second Edition (ADOS–2) which is considered the gold standard for a diagnostic assessment used during a comprehensive evaluation of a person suspected of having an autism spectrum disorder (ASD). To date, 52 licensed professionals have participated in 32 hours of hands-on training in the ADOS-2. Psychologists were targeted because they are the professionals most likely to diagnosis ASD in children; yet only about 10% of them use “gold standard” diagnostic instruments in their assessments.

The Georgia Department of Public Health Autism Initiative collaborates with The Marcus Autism Center (MAC) to improve capacity for early identification of social, communication and behavioral challenges related to ASD and early intervention using evidence-based intervention practices. To date, 127 Early Intervention professionals, across 14 out of the 18 health districts, have received training on the *Autism Navigator*, a web-based course with 5 units and 30 hours of instruction, that uses interactive media to teach evidence-based strategies.