Children with Special Health Care Needs

State Action Plan Table

State Action Plan Table - 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. Increase outreach and awareness activities on health care transition to community stakeholders, youth and families

9.2. Increase the number of training and educational opportunities for health professionals on health care transition

9.3. Improve the standards of care for youth and young adults by implementing health care transition protocols within 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

9.2.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 20 health care transition planning workshops for families and youth

9.2.d. 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

ESM 12.1 - 12.1.1 Promote health care transition through education and training

ESM 12.2 - 12.2.1 Promote health care transition through marketing and media

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 - Children with Special Health Care Needs - Entry 2

Priority Need

Improve access to specialty care for CSHCN

SPM

Improve access to specialty care for CSHCN

Objectives

10.1. Increase outreach and awareness activities on telehealth with medical partners, community stakeholders and families

10.2. Improve the telehealth infrastructure required to support children and youth with special health care needs access to medical care

10.3. Improve the standards of care for children and youth with special health care using telehealth technology

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

Measures

NPM 12 - Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care

Annual Objectives						
	2016	2017	2018	2019	2020	2021
Annual Objective	34.2	34.6	34.9	35.3	35.6	36

Data Source: National Survey of Children with Special Health Care Needs (NS-CSHCN)

Multi-Year Trend

Year	Annual Indicator	Standard Error	Numerator	Denominator
2009_2010	33.9 %	3.4 %	48,646	143,452
2005_2006	37.0 %	3.2 %	43,123	116,600

Legends:

Indicator has an unweighted denominator <30 and is not reportable

Indicator has a confidence interval width >20% and should be interpreted with caution

ESM 12.1 - 12.1.1 Promote health care transition through education and training

Annual Objectives					
2017	2018	2019	2020	2021
Annual Objective	5.0	10.0	15.0	20.0	25.0

ESM 12.2 - 12.2.1 Promote health care transition through marketing and media

Annual Objectives					
2017	2018	2019	2020	2021
Annual Objective	25.0	35.0	50.0	75.0	100.0

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

Priority Need: Improve systems of care for CSHCN

Improve systems of care for CSHCN was identified as a priority need in Georgia that will be addressed through outreach and awareness activities to include training and educational activities, increasing access to specialty care

through telehealth, and developing health care transition protocols within public and private practice settings (state action plan 9.1-9.3).

Outreach and Awareness

In the upcoming year, MCH will develop health care transition materials, a resource portal, provide presentations to community stakeholders, and partner with communities to facilitate the distribution of resources and materials. Workbooks and training curriculum adapted from the Waisman Center (Wisconsin) will be used in education and awareness activities to promote successful health care transition for youth and young adults with and without disabilities. In order to increase awareness of the services available to CSHCN in Georgia, DPH's Child Health website was updated. The website provides a more user-friendly approach to obtaining information about medical homes, transition and local resources.

In the coming year, MCH will also expand partnerships with academic institutions with medical schools, nursing programs and physician assistant programs to plan and define curriculum for CSHCN in clinical programs.

MCH plans to provide an online continuing education module on the Six Core Elements of Health Care Transition to the public health workforce, medical and nursing students, and pediatric and adult providers. MCH host health care transition workshops for families and youth.

In the upcoming year, MCH plans to establish a CSHCN advisory council to support practice improvement efforts, incorporate transition readiness assessments and planning tools, develop a feedback form to measure family satisfaction with transition services, and provide guidance and support to pediatric and adult providers in establishing transition policies.

Priority Need: Improve access to specialty care for CSHCN

Improve access to specialty care for CSHCN was identified as a priority need in Georgia that will be addressed through telehealth (state action plan 10.1-10.3). MCH will 1) increase outreach and awareness activities to medical partners, community stakeholders and families 2) improve our telehealth infrastructure, and 3) improve CSHCN standards of care through telehealth technology.

Outreach and Awareness

In the coming year, MCH will provide comprehensive telehealth information to providers. MCH will also facilitate efforts to educate families about telehealth as an option of care.

Telehealth Infrastructure

MCH will comprise a telehealth stakeholder workgroup for CSHCN, collaborate with DPH's telehealth team to expand telehealth sites, work to expand the telehealth provider network, and collaborate with DPH's epidemiology team to evaluate the current telehealth clinics.

Telehealth Technology

MCH will utilize telehealth to improve care coordination efforts in MCH child health programs, to improve access to audiological and speech therapy services, and to improve access to children and youth with sickle cell disease.

Children with Special Health Care Needs - Annual Report

Annual Report

2015-2016 NPM 02: The percent of children with special health care needs, age 0 to 18 years, whose families partner in decision making at all levels and are satisfied with the care they receive.

Last Year's Accomplishments

All Children's Medical Services (CMS) patients received Care Coordination services, which includes the development of a Care Plan. During FY15, 8,696 families received services from CMS. The Care Plan is developed during the initial visit with a CMS Care Coordinator and updated at a minimum every 6 months. Families are involved in the development of their child's Care Plan which incorporates monitoring and assessment, eliciting feedback regarding satisfaction, and discussing met and unmet needs.

In addition to the CMS Care Plan, all Babies Can't Wait (BCW) families receive Service Coordination, which includes the development of the Individualized Family Service Plan (IFSP). A multidisciplinary team, which includes the service coordinator, family and providers from two disciplines work together to develop an IFSP for the child.

Parents with children with special health care needs were recruited to assist with providing feedback on the Health Care Transition materials for youth and their parents/caregivers. Workbooks and training curriculum adapted from the Waisman Center (Wisconsin) used in education and awareness activities were evaluated by parents. Six parents participated in a half day focus group activity to review materials as well as provide their feedback on updates to the Maternal and Child Health webpage.

During the reporting year, MCH hired another Parent Engagement Specialist to specifically support child health services programmatic activities and quality improvement projects. In addition to MCH's staffed parents of CSHCN,

MCH continued collaboration with Parent to Parent of Georgia to support CMS and BCW programmatic activities.

There are three CMS public health districts that are participate in the Parents as Partners Pilot, a family support initiative that places parents in specialty clinics to enhance support services for CSHCN families. Currently there are two parent partners in private pediatric specialty clinics with Augusta University's Sickle Cell Clinic and Children Health Care of Atlanta's Autism clinic. During the first 12 months 1,100 families of CSHCN were served.

Finally, there will be three Transition to Adult Care Youth Summits. Marketing materials created to promote youth summit participation were distributed to CMS Coordinators and with their families.

Current Activities

MCH continues to provide care and service coordination to CSHCN families through developing Care Plans and IFSPs. Families of children with hearing loss are surveyed through our partner agency, Georgia Pines, to provide satisfaction results, which are used to assist our Early Hearing Detection and Intervention program improvement. Families in our BCW early intervention program are also surveyed prior to exiting the program to if they 1) know their rights 2) can communicate their children's needs and 3) help their children develop and learn. Out of 3,489 completed surveys, 97.1% reported early intervention helped them know their rights, 97.2% reported early intervention has helped them communicate their child's needs, and 96.6% reported early intervention have helped their child develop and learn.

MCH has approximately ten parent leaders that are involved in the EHDI program and family organizations such as Hands and Voices. Six family leaders attended the 2016 National EDHI Conference held in San Diego, CA, one of which was sponsored by MCH. One of the parent leaders was a co-presenter at the EHDI conference alongside MCH's EHDI Coordinator. In the reporting year, four new family leaders were appointed to the Newborn Screening and Genetics Advisory Committee (NBSAC). They represent CSHCN with metabolic disorders, deaf and hard of hearing, sickle cell disease, and cystic fibrosis. These family leaders will work alongside doctors, scientists, and public health professionals to influence the strategic direction of newborn screening and promote policy improvements for the families represented by these specialty areas. Two family leaders were appointed by our Governor to the State Interagency Coordinating Council (SICC) for Early Intervention.

2015-2016 NPM 03: Percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home

Last Year's Accomplishments

Families in BCW and CMS are assessed for participation in a medical home upon enrollment. Through the Integrated Community Systems for CSHCN Grant (D70), knowledge and awareness of the medical home concept was increased.

Staff receives ongoing professional development opportunities via The National Center for Medical Home Implementation webpage and listserv.

All CMS clients are assessed for a medical home, and referrals are made accordingly. 97% of CMS families reported having a primary health care provider.

Through a contract with Parent to Parent of GA, medical and dental home curricula were developed based upon booklets created through our previous Early Childhood and Comprehensive Systems (ECCS) Grant.

Parent to Parent of Georgia partnered with the CMS Program to launch the Parent Partners Project within three public health districts. Medical and Dental Home training was provided to all newly recruited parents to serve as partners in CMS clinics.

Current Activities

The Georgia Department of Public Health has eighteen public health districts, and each district has a child health program. Each child health program consists of Children's 1st (Single Point of Entry for child health referrals), Children's Medical Services (Title V CYSHCN) and Babies Can't Wait (Early Intervention) services.

Within all child health programs, a comprehensive health assessment is completed on families referred to and/or enrolled for services. The Maternal and Child Health Integrated Assessment is the tool used across all child health staff. In FY15, more than 10,000 families were served in the Children's Medical Services program. All of those families in Children's Medical Services received care coordination services, a comprehensive health assessment and care plan was developed with the family's involvement. The care plan is routinely evaluated and updated in partnership with the family as needed but no less frequently than every six (6) months. Families in Babies Can't Wait received early intervention services, evaluations and assessment completed and an Individualized Family Service Plan was developed with the family's involvement. Approximately 15,678 infants and toddlers were enrolled in Babies Can't Wait in SFY14.

The child health program promotes an integrated, team based model of care coordination by conducting weekly Birth to Five meetings to discuss new referrals and status of referrals. Birth to five meetings included staff from Children 1st, Babies Can't Wait and Children's Medical Services. Based on information from the screening and referral form, referrals are either referred to early intervention, chronic illness management or further monitoring services.

The project continues to operate in Public Health and private medical clinic settings. There are four Parent Partners supporting the Parents as Partners project. These four individuals are located in Albany, Atlanta, Gainesville and Augusta. On a monthly basis, these Parents as Partners provide one on one assistance to about 80 families, while the Parent as Partner Manager works individually with each Parent Partner on their continued knowledge and skill development through face-to-face, telephone and email contacts.

The Parents as Partners project will expand to include seven (7) parents at seven (7) different sites in SFY17.

2015-2016 NPM 04: Percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need

Last Year's Accomplishments

Assessing insurance status and coverage for newly enrolled patients is completed during the Children's Medical Services (CMS) and Babies Can't Wait (BCW) program enrollment process. All CMS Care Coordinators utilize the CYSHCN Financial Analysis form to collect family income as well as as insurance and coverage information. CMS Care Coordinators have access to the State Medicaid web portal to complete queries on insurance information for members. For families without insurance during the time of enrollment, CMS Care Coordinators assess eligibility for the State's Medicaid and SCHIP programs and assist with the applications. For families that do not qualify for the

State's Medicaid and SCHIP programs, CMS will serve as the payor of last resort for all healthcare and medical expenses.

For families without insurance during the time of enrollment, CMS Care Coordinators assess eligibility for the State's Medicaid and SCHIP programs and assist with the applications. Care Coordinators continuously check status updates of applications on the State's Medicaid web portal and assist families with completing the requirements of the verification documents. For special cases, CMS Care Coordinators requests additional assistance from the CMS State Office. Regional Directors with the Department of Family and Children Services, entity responsible for Medicaid and SCHIP program enrollment, are contacted to provide guidance and resolution.

The CMS Family Engagement Specialist coordinated a quality improvement project to improve access to incontinence supplies for children and youth with special needs. Medicaid representatives were contacted for clarification on EPSDT coverage and requirements. Medicaid vendors for incontinence supplies were identified and shared with all public health district CMS Coordinators. Sample letters of medical necessity were developed, and also shared with CMS coordinators to assist families in meeting fee-for-service Medicaid requirements. The CMS State Office provided technical assistance for CMS Coordinators having issues with adjusting to the new procedures for authorizing payments for incontinence supplies.

Current Activities

CMS and BCW programs assess insurance status and coverage during the initial enrollment process and annually thereafter.

For families that do not qualify the State's Medicaid and SCHIP programs, CMS and BCW will serve as the payor of last resort for healthcare and medical expenses. Dual enrollment in the CMS and BCW child health programs is permissible.

For families without insurance during the time of enrollment, CMS Care Coordinators assess eligibility for the State's Medicaid and SCHIP programs and assist with the applications. Care Coordinators continuously check status updates of applications on the State's Medicaid web portal and assist families with completing the requirements of the verification documents. For special cases, CMS Care Coordinators requests additional assistance from the CMS State Office. Regional Directors with the Department of Family and Children Services, entity responsible for Medicaid and SCHIP program enrollment, are contacted to provide guidance and resolution.

A Memorandum of Agreement with the Division of Family and Children Services (DFCS) and the Maternal and Child Health (MCH) Section of the Georgia Department of Public Health is under development to improve child health referrals and early intervention services for infants and toddlers birth to three across the State of Georgia.

An initial meeting was held between MCH and DFCS in February 2016 to reestablish the partnership, provide an overview of services available to families and decide on next steps to improving the collaboration. Outlined in the MOA, are quarterly meetings to discuss challenges and opportunities as well as quarterly reports to ensure referrals are processed timely and completely. This opportunity will be used to also address Medicaid enrollment processes and procedures.

The Department of Public Health and the Department of Community Health will sign an agreement to establish a 50 percent Federal Medicaid Funds match on allowable Medicaid-related costs associated with the provision of Babies Can't Wait Special Instruction services to support Medicaid beneficiaries receiving Babies Can't Wait Special Instruction Services.

Children's Medical Services is collaborating with the Amerigroup Georgia Families 360 program to ensure better coordination of services for children and youth in foster care, adoption assistance and juvenile justice. Communication materials were developed for care coordinators supporting the Children's Medical Services program and case managers supporting the Georgia Families 360 program to build awareness of services and eligibility requirements.

2015-2016 NPM 05: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily

Last Year's Accomplishments

There are three CMS district programs that are participants in the Parent as Partners Pilot. The Pilot project enhances support services to CMS families and is provided by a parent with a child with special needs. Parent Partners are trained and knowledgeable on the resources available in their communities. If they are not familiar with a resource they are able to request assistance from Parent to Parent of Georgia and the Department of Public Health.

CMS program administrators received training on coordinating nutrition services for patients with Inborn Errors of Metabolism. The CMS State Office and Newborn Screening programs collaborated with Georgia WIC and Emory Genetics Clinic to host the training offered to all 18 public health districts.

There are two CMS district programs that are participants in the Georgia Asthma Control initiative. The Initiative promotes a multi-trigger, multi-component evidence based asthma intervention. The CMS program will screen and enroll eligible participants, provide care coordination and self- management education, and refer families to a healthy home specialist from Environmental Health.

There are nine public health district CMS programs that partner with local providers to conduct specialty clinics for CYSHCN. Clinics vary from orthopedic to neurology and are most often provided on a monthly basis.

Newborn Screening and CMS are working together to expand telemedicine services in Valdosta, Macon, Waycross and Dublin.

CMS Program coordinators continuously connect families to existing support groups. CMS Care Coordinators connect families with existing support groups facilitated by Parent to Parent of Georgia.

Current Activities

The Georgia Department of Public Health has eighteen public health districts, and each district has a child health program. Each child health program consists of Children's 1st (Single Point of Entry for child health referrals), Children's Medical Services (Title V CYSHCN) and Babies Can't Wait (Early Intervention) services.

All of our child health coordinators routinely participate in community health fairs, school events and marketing campaigns that serve both to inform clients of community resources and to also network and update their community referral resource list, which is disseminated to the families served by child health programs.

Most child health programs have also developed partnerships with local community organizations and national organizations, such as United Way, to ensure consistent service delivery.

There are nine public health districts that partner with local and out of state pediatric subspecialists to conduct specialty clinics for CSHCN. Clinics vary from orthopedic to neurology and are most often provided on a monthly basis. Clinic services are available to families enrolled in the CMS program and reside in the public health district offering the services.

Between July 1, 2015 and March 31, 2016, there were 278 specialty clinics held within nine (9) public health districts, and approximately 3,202 CSHCN were served. Telehealth clinics were held in the Waycross and Valdosta public

health districts and accounted for 67 of those specialty clinics.

Newborn Screening (NBS) and Children's Medical Services (CMS) partners with Augusta University's Sickle Cell Center to provide sickle cell services via on-site and telehealth in three public health districts (Waycross, Dublin and Valdosta). Discussions for the expansion of services to the Albany public health district is in process for sickle cell services.

NBS and CMS is also partnering with a specialist in the areas of pediatrics and genetics to improve access to genetic services via telehealth. A contract between the Department of Public Health and the provider is signed and equipment purchased and installed for services to begin within the next couple of months. The Athens public health district will receive training in the month of April to work with this provider for genetic services.

The Georgia Department of Public Health is committed to establishing a sophisticated telehealth network to underserved areas of Georgia. According to the Georgia Board of Physician Workforce, 52 percent of Georgia's physicians are located in five areas that serve just 38 percent of the state's population. There is adequate partnerships, resources and staff expertise within the Department to allow for continued success within the areas of telehealth.

A Memorandum of Agreement with the Division of Family and Children Services (DFCS) and the Maternal and Child Health (MCH) Section of the Georgia Department of Public Health is under development to improve child health referrals and early intervention services for infants and toddlers birth to three across the State of Georgia. Outlined in the MOA, are quarterly meetings to discuss challenges and opportunities as well as quarterly reports to ensure referrals are processed timely and completely.

The Child Health program is also developing training materials for foster parents and DFCS case managers on child health services offered to families and practical skills in identifying developmental delay with the children they serve.

The Maternal and Child Health contract with Parent to Parent of Georgia, the Family to Family Health Information Center (F2F) and Parent Training Information Center (PTI) was revamped to better align their services with the needs of CYSHCN and their families.

A major shift in the responsibilities for Parent to Parent of Georgia include the Parents as Partners project. The project continues to operate in Public Health and private medical clinic settings to support families of children and youth impacted by special healthcare needs. The project enhances care coordination and support services to Children's Medical Services and Babies Can't Wait families. There are four Parent Partners funded through this contract. These four individuals are located in Albany, Atlanta, Gainesville and Augusta. On a monthly basis, these Parents as Partners provide one on one assistance to about 80 families, while the Parent as Partner Manager works individually with each Parent Partner on their continued knowledge and skill development through face-to-face, telephone and email contacts. The Parents as Partners project will expand to include seven (7) parents at seven (7) different sites in SFY17.

Parent to Parent of Georgia will also continue to provide and maintain a Statewide Central Directory database which allows users to search using various criteria. The database will be used to provide information and referral services for families of children ages birth to twenty-one (21) with developmental delays, disabilities and chronic health care conditions. To improve family support services, parents will be able to access parent training videos as well as the Supporting Parents Program which connects families to other parents with a child with special needs for emotional support. Through the Supporting Parents Program, there are on average thirty-five (35) families that are connected on a monthly basis.

The Maternal and Child Health contract with Easter Seals of West Georgia was revamped to ensure that assistive technology services for preschool kids was utilized by more families and therapists across the State. Marketing and