

Maternal and Child Health Services Title V Block Grant

State Narrative for Georgia

<u>CYSHCN</u>

Application for 2015 Annual Report for 2013



National Performance Measures

Performance Measure 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 services they receive. (CSHCN survey)

| [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)] Annual Objective and Performance | 2009 | 2010 | 2011 | 2012 | 2013 |
|--------------------------------------------------------------------------------------|--------|--------|--------|-------------|-------------|
| Data | | | | | |
| Annual Performance Objective | 56 | 55.1 | 56.2 | 57.3 | 69.4 |
| Annual Indicator | 67.6 | 67.6 | 67.6 | 67.6 | 67.6 |
| Numerator | 279340 | 269807 | 269110 | 269940 | 283089 |
| Denominator | 413225 | 399123 | 398091 | 399320 | 418771 |
| Data Source | NS- | NS- | NS- | NS- | NS- |
| | CSHCN | CSHCN | CSHCN | CSHCN | CSHCN |
| Check this box if you cannot report the | | | | | |
| numerator because | | | | | |
| 1.There are fewer than 5 events over | | | | | |
| the last year, and | | | | | |
| 2.The average number of events over | | | | | |
| the last 3 years is fewer than 5 and | | | | | |
| therefore a 3-year moving average | | | | | |
| cannot be applied. | | | | | |
| Is the Data Provisional or Final? | | | Final | Provisional | Provisional |
| | 2014 | 2015 | 2016 | 2017 | 2018 |
| Annual Performance Objective | 69.4 | 69.4 | 69.4 | 69.4 | |

Tracking Performance Measures

Notes - 2013

Denominator is based on the American Community Survey for years 2007-2012. 2013 was not available. The numerator is based off of the estimated population that was calculated. Query includes by year population under 18 for Georgia.

Notes - 2012

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate this indicator for both the 2001 and the 2005-06 CSHCN survey. However, in 2009-2010 there were wording changes and additions to the questions used to generate this indicator. The data for 2009-2010 are NOT comparable to earlier versions of the survey.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first

conducted in 2001. The same questions were used to generate this indicator for both the 2001 and the 2005-06 CSHCN survey. However, in 2009-2010 there were wording changes and additions to the questions used to generate this indicator. The data for 2009-2010 are NOT comparable to earlier versions of the survey.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Population estimate for children aged 0-17 years was obtained from the OASIS website. The estimate for 2011 were projected using data from 2000 to 2010

CSHCN prevalence for 2005/2006 = 13.9%. This estimate was used for calculating the denominator (CSHCN population) for 2007 and 2008.

CSHCN prevalence for 2009/2010 = 16%. This estimate was used for calculating the denominator for the years 2009, 2010, 2011

Wording for outcome 05/06 which was used for the indicator for 2007 and 2008- CSHCN whose families are partners in decision-making at all levels and are satisfied with the services they receive (derived)

Wording for outcome 09/10 which was used for the indicator for 2009, 2010 and 2011 - CSHCN whose families partner in shared decision-making for child's optimal health (Note. This estimate is not comparable to estimates for 2007/2008 which were obtained from the 2005/2006 survey)

The data from the two surveys are not comparable for PM 02

Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM02 indicator for both the 2001 and the

2005-2006 CSHCN survey. The annual indicator will reflect the data from this survey until a new data source or an updated survey is available.

Numerator and denominator estimates were made. These estimates are important to demonstrate that while the percent remains constant the number of affected children increased as the population grows. Numerator data were estimated by multiplying the percent by the denominator. The denominator is estimated by multiplying the CSHCN prevalence (13.9%) by the total number of children ages birth to 17 years. The total number of children ages birth to 17 years. The total number of children projections provided by OASIS. Population projections were not available for 2010. The population estimate for 2010 was estimated using a linear projection with data from 2000 through 2009.

Sufficient data are not available to use a projection to forecast the annual performance objective between 2011 through 2015. An anticipated 2% increase will be applied to the annual performance objective in 2010.

a. Last Year's Accomplishments

CMS Coordinators developed a plan of care (POC) for 100% of CYSHCN clients, with families participating in the determination of the priority for their child's needs. CMS Coordinators review the plan of care with families every 6 months. BCW Coordinators develop an (IFSP) with100% of enrolled families within a 45 day timeframe prior to services being performed. Families help determine the priority for their child's needs.

Parent to Parent of Georgia (P2PGA) provided online training to 165 families of children with disabilities or chronic medical conditions. P2PGA also fielded 10,752 family and professional requests for disability specific information and resources from their online database.

The DPH/MCH Parent Consultant developed an online family leadership training module that will be made available on the DPH/MCH/CYSN webpage for families to view.

Families participating in Part C Early Intervention Services/Babies Can't Wait (BCW) reported that early intervention services have helped the family:

- A) Know their rights
- B) Communicate their children's needs
- C) Help their children develop and learn

CMS epidemiologist developed a family satisfaction survey as a result of program improvement efforts, which included parents and grandparents of children receiving CMS services.

| Activities | Pyram | id Leve | l of Serv | vice |
|---------------------------------------------------------------------|-------|---------|-----------|------|
| | DHC | ES | PBS | IB |
| 1. Continuing family participation through development of CMS | | Х | | |
| care coordination plan of care and BCW IFSP development. | | | | |
| 2. Conducting CYSHCN family satisfaction surveys statewide as | | | | Х |
| an ongoing part of quality assurance programmatic/ fiscal review. | | | | |
| 3. Conducting client satisfaction surveys annually in the Genetics | | | | Х |
| and Sickle Cell clinics. Surveys are offered in English and | | | | |
| Spanish. | | | | |
| 4. Continue to involve families in state and local program planning | | | | Х |
| and operations. | | | | |
| 5. | | | | |
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| 10. | | | | |

Table 4a, National Performance Measures Summary Sheet

b. Current Activities

Activity 1: Involve families of CSHCN receiving services from CMS in the development of plans of care.

The FY13 unduplicated count of CMS families served was 10,983. Plans of care were reviewed with families every 6 months. The FY13 unduplicated count of families served for BCW was 16,411. BCW collaborated with families to develop individual family service plans IFSP(s).

Activity 2: Plan for the development of an online family leadership training module.

Parent to Parent of Georgia (P2PGA) provided 165 online training opportunities for families of children with disabilities or chronic medical conditions. P2PGA completed a second round of transition to adulthood webinars with youth as presenters or co-presenters alongside professionals. Also, the DPH/MCH Parent Consultant developed an online family leadership training module which was added to the DPH/MCH/CYSN webpage.

Activity 3: Survey CYSN families participating in Part C Early Intervention Services/Babies Can't Wait (BCW), and families receiving genetic services through CMS clinics.

BCW families reported that early intervention services have helped them:

- A) Know their rights -
- B) Communicate their children's needs -
- C) Help their children develop and learn -

Families participating in Genetics and Sickle Cell clinics reported that they either strongly agree or agree to the following:

- A) Satisfied with services received at clinic visit
- B) Needs were met during clinic visit

These same families reported that they strongly disagreed or disagreed to the following:

C) Satisfied with timeliness of getting an appointment

D) Learned adequate information about their child's condition (most of which were based upon first clinic visit)

Activity 4: Involve families in state and local program planning and operations by including them in activities such as reviewing materials, serving on committees and councils, attending trainings, co-presenting with professionals, providing presentations and trainings to families and professionals, providing support and health information to other families.

Families were chosen to participate as team members in BCW State Interagency Council Subcommittee program planning activities, the Child Health Restructuring Committee, the BCW Taskforce, CMS Program Improvement activities, the Title V Block Grant Review. Also, families and youth were an integral part of the D70 Youth Summit serving as planning committee members, and as panelists, keynote speakers and presenters.

c. Plan for the Coming Year

Activity 1: Involve families of CYSHCN receiving services from CMS and BCW in the development of plans of care (POC) and individual family service plan (IFSP).

Output Measure(s): Number of families with input on plans of care or individual family service plans and BCW IFSP plans.

Monitoring: Quarterly Reports

Activity 2: Increase family knowledge and participation in block grant activities

Output Measure(s): Number of families involved in block grant activities; development of family-friendly materials and resources on block grant process

Monitoring: Informational materials developed; Block grant family participation form

Activity 3: Survey CYSN families for satisfaction in services and support

Output Measure(s): BCW Family Participation Results; Genetics/Sickle Cell Satisfaction Survey Results, CMS Family Satisfaction Survey(s)

Monitoring: Quarterly Reports

Activity 4: Increase opportunities for family participation in DPH/MCH/CYSN activities and trainings

Output Measure(s): Number of participation opportunities provided

Monitoring: Quarterly Reports

Performance Measure 03: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)

Tracking Performance Measures

| [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)] Annual Objective and Performance | 2009 | 2010 | 2011 | 2012 | 2013 |
|--------------------------------------------------------------------------------------|--------|--------|--------|-------------|-------------|
| Data | | | | | |
| Annual Performance Objective | 51 | 52 | 53.1 | 54.1 | 53.1 |
| Annual Indicator | 67.6 | 67.6 | 67.6 | 67.6 | 45.7 |
| Numerator | 279340 | 269807 | 269110 | 269940 | 191378 |
| Denominator | 413225 | 399123 | 398091 | 399320 | 418771 |
| Data Source | NS- | NS- | NS- | NS- | NS- |
| | CSHCN | CSHCN | CSHCN | CSHCN | CSHCN |
| Check this box if you cannot report the | | | | | |
| numerator because | | | | | |
| 1.There are fewer than 5 events over | | | | | |
| the last year, and | | | | | |
| 2.The average number of events over | | | | | |
| the last 3 years is fewer than 5 and | | | | | |
| therefore a 3-year moving average | | | | | |
| cannot be applied. | | | | | |
| Is the Data Provisional or Final? | | | Final | Provisional | Provisional |
| | 2014 | 2015 | 2016 | 2017 | 2018 |
| Annual Performance Objective | 53.1 | 53.1 | 53.1 | 53.1 | |

Notes - 2013

Denominator is based on the American Community Survey for years 2007-2012. 2013 was not available. The numerator is based off of the estimated population that was calculated. Query includes by year population under 18 for Georgia.

Notes - 2012

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001

CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. The data for the 2001 and 2005-2006 surveys are not comparable for NPM 3. However, the same questions were used to generate the NPM 3 indicator for both the 2005-2006 and 2009-2010, therefore these two surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. The data for the 2001 and 2005-2006 surveys are not comparable for NPM 3. However, the same questions were used to generate the NPM 3 indicator for both the 2005-2006 and 2009-2010, therefore these two surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Population estimate for children aged 0-17 years was obtained from the OASIS website. The estimate for 2011 were projected using data from 2000 to 2010 prevalence for 2005/2006 = 13.9%. This prevalence was used for calculating the denominator (CSHCN population) for 2007 and 2008. CSHCN prevalence for 2009/2010 = 16%. This prevalence was used for calculating the denominator for the years 2009, 2010, 2011

Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions and additions to the questions used to generate the NPM03 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #03.

The annual indicator will reflect the data from this survey until a new data source or an updated survey is available.

Numerator and denominator estimates were made. These estimates are important to demonstrate that while the percent remains constant the number of affected children increased as the population grows. Numerator data were estimated by multiplying the percent by the denominator. The denominator is estimated by multiplying the CSHCN prevalence (13.9%) by the total number of children ages birth to 17 years. The total number of children ages birth to 17 years. Population projections were not available for 2010. The population estimate for 2010 was estimated using a linear projection with data from 2000 through 2009.

Sufficient data are not available to use a projection to forecast the annual performance objective between 2011 through 2015. An anticipated 2% increase will be applied to the annual performance objective in 2010.

a. Last Year's Accomplishments

A medical and dental home training and booklets were developed and presented. Through the new Integrated Community Systems for CSHCN Grant, P2PGA was contracted to extend this training in our health districts. Agencies that attended the training requested a total of 10,471 booklets and brochures to distribute throughout the state to families and professionals. Of that total, 1,650 requests were for a Spanish version of the developmental milestones brochure.

CMS Coordinators and BCW Service Coordinators assess whether or not clients have a primary care provider (PCP) upon enrollment and every 6 months, thereafter. Coordinators make

referrals for those clients who do not have a PCP. 76% of CMS clients reported having a PCP.

Meetings with representatives from GA AFP and GA AAP to review contract deliverables and timelines have occurred. Through our Integrated Community Systems for CSHCN contracts with GA AFP and GA AAP, both organizations will require its members to complete an online training on medical home.

| Table 4a, National Performance Measures Summary Sheet Activities | Pyram | id Leve | l of Serv | /ice |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|---------|-----------|------|
| | DHC | ES | PBS | IB |
| 1. Continuing CSHCN participation in the Integrated Community Systems for CSHCN (D70) grant. One component of the grant is the development of a statewide transition plan for youth with special health care needs. This includes partnering with other agencies and community partners to collaborate on transition efforts and increase knowledge of and access to medical home(s). | | | | X |
| 2. Continuing to facilitate CSHCN program enrollees accessing a medical home. | | Х | | |
| 3. Documenting the percentage of CSHCN enrollees who have a documented medical home. | | Х | | |
| 4. Referring CSHCN without a medical home to a primary care provider. | | Х | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |

Table 4a, National Performance Measures Summary Sheet

b. Current Activities

Activity 1: Work with GA-AAP and GA-AFP to increase professional development opportunities to state and district level staff and medical and non-medical providers on the definition and components of a medical home.

Dr. Jeoffrey White, Georgia's first pediatric practice to receive national Medical Home certification, presented on medical home and transition. Dr. White was also recognized as DPH's physician of the year for FY13. GA-AAP created a page on the Chapter's website regarding transition and archived webinars pertaining to transition and medical home. GAFP provided an overview of the Patient Centered Medical Home University to DPH staff. GA-AAP and GA-AFP provided a dedicated "Chapter Champion" to help promote Medical Home and Transition initiatives of the Integrated Community Systems for Georgia's CSHCN.

Georgia has made tremendous progress in increasing the number of certified medical home providers. Within a period of about two years, Georgia saw an increase from approximately 250 certified medical home providers/ practices to over 1,000.

Activity 2: Assess new BCW and CMS clients for a primary care provider and make appropriate referrals for clients without a medical home.

Upon enrollment families in BCW and CMS were assessed to whether or not they had a medical home. 95% of CMS families reported having a primary care provider. Upon enrollment BCW Coordinators assessed families for access to a medical home. Referrals to a primary care provider were made as needed.

We made great strides through our Integrated Community Systems for CSHCN Grant (D70) to increase knowledge and awareness of the medical home concept. We targeted families, providers and community partners. Through a contract with P2PGA, medical and dental home curricula were developed based upon booklets created through our previous Early Childhood and Comprehensive Systems (ECCS) Grant. Curricula presentations were then recorded in English and Spanish by DPH. The presentations will be made available online to families, professionals and district staff. Also, districts that serve clients at clinics will have access to CDs to play for families while they wait for clinic services.

Activity 3: Partner with Parent to Parent of Georgia to provide a training curriculum, materials and outreach activities on Medical and Dental Home.

Contracted with Parent to Parent of Georgia to develop a medical and dental home curriculum using the brochures developed by the ECCS grant. DPH then hosted P2PGA parents to create presentations using the curriculum to distribute as CDs to districts hosting clinics, and to add to the DPH internal and external website for viewing by state and district staff as well as families and professionals. An additional 200 Medical home fact sheets were distributed statewide to families and professionals. P2PGA added certified Medical Home providers to their database for access by families and professionals.

c. Plan for the Coming Year

Activity 1: Work with GA-AAP and GA-AFP to increase professional development opportunities to state and district level staff and medical and non-medical providers on the definition and components of a medical home.

Output Measure(s): Number of trainings; staff trained; positive change in baseline knowledge, and number of brochures distributed

Monitoring: AAP & AFP Quarterly Reports

Activity 2: Assess new BCW and CMS clients for a primary care provider and make appropriate referrals for clients without a medical home.

Output Measure(s): Number of clients who have been assessed for a primary care provider; number of referrals provided to clients who did not have a primary care provider

Monitoring: Quarterly Reports

Activity 3: Partner with Parent to Parent of Georgia to provide a training curriculum, materials and outreach activities on Medical and Dental Home.

Output Measure(s):Number of trainings; number of participants trained; number of medical and dental home brochures and fact sheets distributed

Monitoring: Quarterly program reports from Parent to Parent of Georgia

Performance Measure 04: The 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. (CSHCN Survey)

| Tracking Performance Measures |
|--------------------------------------------------|
| [Case 495 (2)(2)(D)(iii) and 490 (a)(2)(A)(iii)] |

| [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)] Annual Objective and Performance | 2009 | 2010 | 2011 | 2012 | 2013 |
|--------------------------------------------------------------------------------------|--------|--------|--------|-------------|-------------|
| Data | | | | | |
| Annual Performance Objective | 62 | 62.4 | 63.7 | 64.9 | 63.7 |
| Annual Indicator | 62.2 | 62.2 | 62.2 | 62.2 | 62.2 |
| Numerator | 257026 | 248255 | 248160 | 248377 | 260476 |
| Denominator | 413225 | 399123 | 398091 | 399320 | 418771 |
| Data Source | NS- | NS- | NS- | NS- | NS- |
| | CSHCN | CSHCN | CSHCN | CSHCN | CSHCN |
| Check this box if you cannot report the | | | | | |
| numerator because | | | | | |
| 1.There are fewer than 5 events over | | | | | |
| the last year, and | | | | | |
| 2.The average number of events over | | | | | |
| the last 3 years is fewer than 5 and | | | | | |
| therefore a 3-year moving average | | | | | |
| cannot be applied. | | | | | |
| Is the Data Provisional or Final? | | | Final | Provisional | Provisional |
| | 2014 | 2015 | 2016 | 2017 | 2018 |
| Annual Performance Objective | 63.7 | 63.7 | 63.7 | 63.7 | |

Notes - 2013

Denominator is based on the American Community Survey for years 2007-2012. 2013 was not available. The numerator is based off of the estimated population that was calculated. Query includes by year population under 18 for Georgia.

Notes - 2012

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate the NPM 4 indicator for the 2001,

2005-06, and 2009-2010 CSHCN surveys.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate the NPM 4 indicator for the 2001, 2005-06, and 2009-2010 CSHCN surveys.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Population estimate for children aged 0-17 years was obtained from the OASIS website. The estimate for 2011 was projected using data from 2000 to 2010 CSHCN prevalence for 2005/2006 = 13.9%. This prevalence was used for calculating the denominator (CSHCN population) for 2007 and 2008. CSHCN prevalence for 2009/2010 = 16%. This prevalence was used for calculating the denominator for the years 2009, 2010, and 2011

Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-

2006. The same questions were used to generate the NPM04 indicator for both the 2001 and the 2005-2006 CSHCN survey.

The annual indicator will reflect the data from this survey until a new data source or an updated survey is available.

Numerator and denominator estimates were made. These estimates are important to demonstrate that while the percent remains constant the number of affected children increased as the population grows. Numerator data were estimated by multiplying the percent by the denominator. The denominator is estimated by multiplying the CSHCN prevalence (13.9%) by the total number of children ages birth to 17 years. The total number of children ages birth to 17 years. The total number of children ages birth to 17 years is from population projections provided by OASIS. Population projections were not available for 2010. The population estimate for 2010 was estimated using a linear projection with data from 2000 through 2009.

Sufficient data are not available to use a projection to forecast the annual performance objective between 2011 through 2015. An anticipated 2% increase will be applied to the annual performance objective in 2010.

a. Last Year's Accomplishments

CMS Coordinators and BCW Service Coordinators assessed 100% of clients for insurance coverage upon enrollment and every six months thereafter. In fourth quarter 2013, 87% of CMS clients were covered by insurance or another health care payment source; 13% were uninsured with CMS as the only payor source. CMS is the payor of last resort.

CMS Coordinators and BCW Service Coordinators refer clients identified as uninsured to Georgia's Department of Family and Children Services to apply for Medicaid, PeachCare for Kids (SCHIP) and other social services resources.

Table 4a, National Performance Measures Summary Sheet

| Activities | Pyram | id Leve | l of Serv | vice |
|----------------------------------------------------------------------------------------------------------------------------------------|-------|---------|-----------|------|
| | DHC | ES | PBS | IB |
| 1. Monitoring payment sources for services (i.e., types of insurance or payment source) and referring families to potential resources. | | | | Х |
| 2. Developing a plan to identify the diverse needs of families not covered by insurance. | | | | Х |
| 3. Continuing to work with Medicaid and PeachCare for Kids (State Child Health Insurance Program) to link all eligible children. | | X | | |
| 4. | | | | |
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| 9. | | | | |

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b. Current Activities

Activity 1: Assess insurance status and coverage of new clients in CMS and BCW

CMS clients: 72% Medicaid, 5% PeachCare for Kids (SCHIP), 9% Private, 1% Tricare, 13% CMS only.

Activity 2: Assist CMS and BCW clients to apply for Medicaid and other insurance or health care financing benefits

72% of CMS clients are covered by Medicaid; 5% PeachCare for Kids (SCHIP); 32% of CMS clients receive SSI.

Activity 3: Work in partnership with GA State Medicaid agency and managed care organizations to increase adequacy of coverage for CSHCN

The CMS and BCW Program Managers were invited to participate on the Medicaid Georgia Families 360 Taskforce to migrate children receiving foster care and/or adoptive assistance to Care Managed Organizations (CMOs). As a result of their participation, children and youth with special needs within this population were allowed to be exempted from coverage through the CMO. It was determined that CYSHCN with more intensive medical needs would receive a higher level of care coordination through fee-for-service Medicaid and Children Medical Services (CMS). Also, BCW providers were added as CMO network providers, thereby reducing delays in services for children receiving early intervention services. Lastly, the Care Management Organization provided training to state and district office staff, as well as, providers.

c. Plan for the Coming Year

Activity 1: Assess insurance status and coverage of new clients in CMS and BCW.

Output Measure(s): Annual report of insurance coverage in CMS and BCW; percent of new clients assessed; percent with insurance coverage by type of coverage.

Monitoring: CMS Quarterly Reports/BCW Data Report (Medicaid / CMOs/Private Insurance Activity 2: Assist CMS and BCW clients to apply for Medicaid and other insurance benefits.

Output Measure(s): Number of family referrals to Medicaid, insurance and other health care financing options

Monitoring: Quarterly reports

Activity 3: Work in partnership with GA State Medicaid agency and managed care organizations to increase adequacy of coverage for CSHCN

Output Measure(s): Number of partnership activities completed

Monitoring: Create new and engage in existing Medicaid partnership activities

Performance Measure 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. (CSHCN Survey)

Tracking Performance Measures

| Annual Objective and Performance | 2009 | 2010 | 2011 | 2012 | 2013 |
|-----------------------------------------|--------|--------|--------|-----------|-------|
| Data | | | | | |
| Annual Performance Objective | 92 | 92.8 | 94.7 | 96.6 | 98.5 |
| Annual Indicator | 69.5 | 69.5 | 69.5 | 69.5 | |
| Numerator | 287289 | 277061 | 277285 | 296192 | |
| Denominator | 413365 | 398648 | 398972 | 426175 | |
| Data Source | NS- | NS- | NS- | NS- | NS- |
| | CSHCN | CSHCN | CSHCN | CSHCN | CSHCN |
| Check this box if you cannot report the | | | | | |
| numerator because | | | | | |
| 1.There are fewer than 5 events over | | | | | |
| the last year, and | | | | | |
| 2. The average number of events over | | | | | |
| the last 3 years is fewer than 5 and | | | | | |
| therefore a 3-year moving average | | | | | |
| cannot be applied. | | | | | |
| Is the Data Provisional or Final? | | | Final | Provision | |
| | 2014 | 2015 | 2016 | 2017 | 2018 |
| Annual Performance Objective | 100 | 100 | 100 | 100 | |

Notes - 2013

Denominator is based on the American Community Survey for years 2007-2012. 2013 was not available. The numerator is based off of the estimated population that was calculated. Query includes by year population under 18 for Georgia.

Notes - 2012

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001

CSHCN survey, there were revisions to the wording, order, and number of questions used to generate this indicator for the 2005-06 CSHCN survey. The questions were also revised extensively for the 2009-2010 CSHCN survey. Therefore, none of the three rounds of the surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001

CSHCN survey, there were revisions to the wording, order, and number of questions used to generate this indicator for the 2005-06 CSHCN survey. The questions were also revised extensively for the 2009-2010 CSHCN survey. Therefore, none of the three rounds of the surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Population estimate for children aged 0-17 years was obtained from the OASIS website. The estimate for 2011 were projected using data from 2000 to 2010 CSHCN prevalence for 2005/2006 = 13.9%. This prevalence was used for calculating the denominator (CSHCN population) for 2007 and 2008. CSHCN prevalence for 2009/2010 = 16%. This prevalence was used for calculating the denominator for the years 2009, 2010, 2011 The data from the two surveys are not comparable for PM 05

Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were revisions to the wording, ordering and the number of the questions used to generate the NPM05 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #05.

The annual indicator will reflect the data from this survey until a new data source or an updated survey is available.

Numerator and denominator estimates were made. These estimates are important to demonstrate that while the percent remains constant the number of affected children increased as the population grows. Numerator data were estimated by multiplying the percent by the denominator. The denominator is estimated by multiplying the CSHCN prevalence (13.9%) by the total number of children ages birth to 17 years. The total number of children ages birth to 17 years. Population projections provided by OASIS. Population projections were not

available for 2010. The population estimate for 2010 was estimated using a linear projection with data from 2000 through 2009.

Sufficient data are not available to use a projection to forecast the annual performance objective between 2011 through 2015. An anticipated 2% increase will be applied to the annual performance objective in 2010.

a. Last Year's Accomplishments

CMS served 8806 clients in the first quarter and 8846 clients in the second. CMS Coordinators made a total of 675 referrals to community resources. BCW and CMS families have access to online and one-to-one support to help find resources for families of CYSHCN. The CMS program conducts clinics in 9 of 18 health districts. Clinics located in rural areas of the state provide access to communities with limited specialty services. DPH has initiated the use of telemedicine to supplement face-to-face clinics where appropriate. DPH began distributing 13 telemedicine carts to health districts around the state to expand the network of clinical services offered. DPH has also implemented a telehealth network for public health education in all counties.

Table 4a, National Performance Measures Summary Sheet

| Activities | Pyramid Level of Servi | | vice | |
|-----------------------------------------------------------------------------------------------------------------------|------------------------|----|------|----|
| | DHC | ES | PBS | IB |
| 1. Gathering data from other states and MCHB sponsored contracts that have completed previous work in this area. | | | | Х |
| 2. Conducting ongoing CMS family satisfaction surveys and data collection as part of CMS quality improvement process. | | | | Х |

| 3. Promoting the use of Federally Qualified Health Centers to clients with Sickle Cell Disease (through Sickle Cell Foundation of Georgia). | | Х | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|---|--|
| 4. Providing funds to the public health districts to assist patients with the cost of genetic testing. | Х | | |
| 5. Offering Transcranial Doppler (TCD) ultra-sonograms to pediatric Sickle Cell patients ages 2 to 16 years in 10 pediatric Sickle Cell outreach clinics. | Х | | |
| 6. Holding telemedicine clinics in Waycross and Valdosta to enable families to see medical specialists at Georgia Health Sciences University in Augusta, Georgia and Shands Hospital in Jacksonville, Florida. | Х | | |
| 7. | | | |
| 8. | | | |
| 9. | | | |
| 10. | | | |

b. Current Activities

Activity 1: Assist families served in CMS with accessing available community resources (CMS/BCW/C1st)

At risk children, age birth to five, are referred to community resources through our Children's 1st (C1st - point of entry) program. C1st served 13,376 families, BCW served 16,411 families and CMS served 10,983 families during FY13. BCW and CMS families are regularly referred to community resources. Parent to Parent of Georgia serves as our BCW Central Directory for CSHCN ages birth to three, and they also provide information and referral services to Title V families for CSHCN ages birth to twenty-one. Through our D70 Integrated Community Services for CSHCN, P2P received 1,688 online page view requests for transition-related information. The highest number of requests was for: general information on transition (516), transition planning (286), and independent living skills (199). P2P received 5,739 page view requests for health-related information. The highest number of requests was for: Katie Beckett/Deeming Waiver (1,583), general Medicaid information (1,043), general healthcare information (674), Medicaid residency & citizenship (377), and financial assistance for health (243). Medical home received 151 page view requests. (Data reported over three quarters)

Activity 2: Conduct specialty clinics for CYSHCN in areas with limited specialty providers/services (CMS/BCW/C1st)

The CMS program conducted clinics in 9 of 18 health districts. Clinics located in rural areas of the state provided access to communities with limited specialty services.

Activity 3: Expand telemedicine services in targeted health districts based on data and need (CMS).

We've provided training on telemedicine to all district coordinators and have suggested those with clinics continue researching the feasibility of using telemedicine for their clinics with TA and support provided by the state office.

Georgia Regents University (GRU) sickle cell disease physicians have completed an equipment demonstration, an online telemedicine certification training, and are currently pursuing their credentials. They are also finalizing billing and reimbursement processes as well.

Activity 4: Connect families to existing, or create new support groups or disability community

activities for CYSHCN within their districts.

Through a contract with P2P, local family leaders will be trained to start new support groups or connect with existing organized groups to share information and supports for CSHCN (6 per year)

c. Plan for the Coming Year

Activity 1: Assist families served in CMS with accessing available community resources (CMS/C1st)

Output Measure(s): Number of referrals made to community

resources). Monitoring: Quarterly reports.

Activity 2: Conduct specialty clinics for CYSHCN in areas with limited specialty providers/services (C1st/CMS).

Output Measure(s): number of clinics

conducted. Monitoring: Quarterly reports.

Activity 3: Expand telemedicine services in targeted health districts based on data and need (CMS).

Output Measure(s): Number of new telemedicine sites; number of specialties represented; number of clients served at telemedicine sites.

Monitoring: Quarterly reports.

Activity 4: Connect families to existing, or create new support groups or disability community activities for CYSHCN within their districts

Output Measure(s): Number of CMS families connected to support groups or disability community activities

Monitoring: Quarterly reports.

Performance Measure 06: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

| [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)] | | | | | |
|--------------------------------------------------|--------|--------|--------|--------|------|
| Annual Objective and Performance | 2009 | 2010 | 2011 | 2012 | 2013 |
| Data | | | | | |
| Annual Performance Objective | 38 | 37.7 | 38.5 | 39.3 | 37.7 |
| Annual Indicator | 33.9 | 33.9 | 33.9 | 33.9 | |
| Numerator | 140131 | 135142 | 135251 | 144473 | |

Tracking Performance Measures

| Denominator | 413365 | 398648 | 398972 | 426175 | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|--------|--------|-----------|-------|
| Data Source | NS- | NS- | NS- | NS- | NS- |
| | CSHCN | CSHCN | CSHCN | CSHCN | CSHCN |
| Check this box if you cannot report the numerator because 1.There are fewer than 5 events over the last year, and 2.The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. | | | | | |
| Is the Data Provisional or Final? | | | Final | Provision | |
| | 2014 | 2015 | 2016 | 2017 | 2018 |
| Annual Performance Objective | 37.7 | 37.7 | 37.7 | 37.7 | |

Notes - 2013

Denominator is based on the American Community Survey for years 2007-2012. 2013 was not available. The numerator is based off of the estimated population that was calculated. Query includes by year population under 18 for Georgia.

Notes - 2012

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001

CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the 2 surveys are not comparable for NPM 6, and findings from the 2005-06 survey may be considered baseline data. However, the same questions were used to generate the NPM 6 indicator for the 2009-

2010 survey. Therefore, the 2005-2006 and 2009-2010 surveys can be compared.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001

CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the 2 surveys are not comparable for NPM 6, and findings from the 2005-06 survey may be considered baseline data. However, the same questions were used to generate the NPM 6 indicator for the 2009-

2010 survey. Therefore, the 2005-2006 and 2009-2010 surveys can be compared.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

Population estimate for children aged 0-17 years was obtained from the OASIS website.

The estimate for 2011 were projected using data from 2000 to 2010 CSHCN prevalence for 2005/2006 = 13.9%. This prevalence was used for calculating the denominator (CSHCN population) for 2007 and 2008. CSHCN prevalence for 2009/2010 = 16%. This prevalence was used for calculating the denominator for the years 2009, 2010, 2011

Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate the NPM06 indicator for the 2005-2006

CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the two surveys are not comparable for PM #06 and the 2005-2006 may be considered baseline data.

The annual indicator will reflect the data from this survey until a new data source or an updated survey is available.

Numerator and denominator estimates were made. These estimates are important to demonstrate that while the percent remains constant the number of affected children increased as the population grows. Numerator data were estimated by multiplying the percent by the denominator. The denominator is estimated by multiplying the CSHCN prevalence (13.9%) by the total number of children ages birth to 17 years. The total number of children ages birth to 17 years. Population projections provided by OASIS. Population projections were not

available for 2010. The population estimate for 2010 was estimated using a linear projection with data from 2000 through 2009.

Sufficient data are not available to use a projection to forecast the annual performance objective between 2011 through 2015. An anticipated 2% increase will be applied to the annual performance objective in 2010.

a. Last Year's Accomplishments

CMS Coordinators are required to develop a transition plan with the client and their family beginning no later than age 16 and review the plan every six months thereafter. Parent to Parent of Georgia was contracted to conduct four focus groups to gather input to update the CMS Transition Manual. Through the D70 State Integrating Systems of Services for CYSHCN Grant, statewide stakeholder meetings were scheduled to develop a statewide plan for Transition to Adulthood to improve transition in six core areas: Education, Health, Employment, Legal Issues, Independent and Community Living, and Recreation and Leisure.

| Activities | | Pyramid Level of Service | | | | |
|-----------------------------------------------------------------------------------------------------------------------------|-----|--------------------------|-----|----|--|--|
| | DHC | ES | PBS | IB | | |
| 1. Continuing to provide literature and updates on transition services to district coordinators. | | X | | | | |
| 2. Continuing to update the CMS transition manual and materials for district coordinators to use with clients and families. | | | | Х | | |
| 3. Collecting data on percent of clients and families with a transitional plan of care. | | | | Х | | |

Table 4a, National Performance Measures Summary Sheet

| 4. Developing webinar series to train families, professionals, and district coordinators on transition of youth with special health care needs to all aspects of adulthood. | Х | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|--|
| 5. | | |
| 6. | | |
| 7. | | |
| 8. | | |
| 9. | | |
| 10. | | |

b. Current Activities

Activity 1: Develop transition plans for CMS clients ages 16 to 21 years.

94% of CMS clients aged 16-21 had active transition plans.

Activity 2: Partner with Parent to Parent of Georgia (GA's Family to Family Health Information Center) to revise the CMS Transition Manual

Parent to Parent conducted 4 statewide focus groups, one of which was held in Spanish, and one which was held with youth only. CMS coordinators will have an opportunity to provide their input; then, families will have an opportunity to view the proposed updates prior to the finalization of the updates. Afterwards, CMS districts and families will be trained on the changes.

Activity 3: Partner with GA-AFP, GA-AAP to provide information and training opportunities to physicians to increase their understanding of transition planning.

Dr. David Levine was identified as the GA-AAP Chapter Champion for transition services to assist in facilitating and promoting the Integrated Community Systems for CYSHCN to society membership. Two physician trainings completed at the Pediatric by the Sea conference. Dr. Peter Lane presented on "Sickle Cell Disease in Georgia – from Newborn Screening to Transition." Dr. Jeoffrey White presented on medical home and transition. GA-AAP created a page on the Chapter's website regarding transition and archived webinars pertaining to transition and medical home. DPH in collaboration with GA-AAP and GAFP is developing a "Physicians Guide to Transitioning Youth from Pediatric Primary Care to Adult Primary Care" to assist practitioners in implementing the six core elements of health care transition. GA-AFP made available free CME program on the chapter's website "Promotion of Transition Care of the Sickle Cell Patient – New Insights to Management" presentation by Dr. James Eckman. GA-AFP published an article in the national Chapter's Practical Playbook titled "Georgia Provides Transition Care Plan for Children with Special Health Care Needs."

Activity 4: Connect families to transition resources to promote transition to adulthood.

GA DPH/MCH/CYSN developed a webpage to host D70 transition and medical home materials and resources for families and professionals. Parent to Parent of Georgia enhanced their website, database, virtual library, and "Roadmap to Services" (pictorial map) with transition related materials. DPH contracted with Parent to Parent to develop and conduct peer leadership and transition to adulthood trainings for youth peer mentors, and to train transition-aged youth to serve as peer mentors for others dealing with transition to adulthood issues such as accessing insurance, being successful in college, etc. This is similar to their Parent to Parent Support Model. Lastly, Parent to Parent developed separate e-communities to connect youth, families and professionals using social media tools and resources. To date the youth community has approximately 75 members and the parent/family community has approximately 150 members.

DPH contracted with Children's Healthcare of Atlanta (CHOA) to enhance and replicate their Sickle Cell Transition to Adult Healthcare Mentorship Program. CHOA volunteered to work with DPH to conduct continuous improvement activities using the PDSA (Plan, Study, Do, Act) Tool for their mentorship program.

Activity 5: Partner with community partners to host a Youth Transition Summit

Through the D70 Grant, MCH partnered with Georgia State University's Center for Leadership in Disability (GA Lend Program) to host a statewide youth transition summit. Presentations covered the six key areas of transition: Education, Health, Independent and Community Living, Recreation and Leisure, Legal Issues, and Employment. Youth participated as presenters and panelists. There was also a separate track for parents. Statewide Partners for the event included: GA Department of Public Health, GA State University-Center for Leadership in Disability, University of GA-Fanning Institute, GA Council on Developmental Disabilities, disABILITY LINK (Self-Advocates), Special Olympics Georgia, Disability Resource Center, All About Developmental Disabilities, Kennesaw State University, Georgia Vocational Rehabilitation Agency and Parent to Parent of GA. One of Georgia's State Senators was in attendance to support his youth with special needs. Over 100 youth, family members and professionals attended the summit. Organizers would like to replicate the event in Middle and South Georgia.

c. Plan for the Coming Year

Activity 1: Develop transition plans for CMS clients ages 16 to 21 years.

Output Measure(s): Percentage of CMS clients who have a documented transition plan.

Monitoring: Quarterly reports from CMS staff.

Activity 2: Partner with Parent to Parent to revise the CMS Transition Manual.

Output Measure(s): Updated manual; number of focus groups conducted

Monitoring: Parent to Parent monthly programmatic report, statewide training plan.

Activity3: Partner with GA-AAP and GA-AFP to provide information and training opportunities to physicians to increase their understanding of transition planning.

Output Measures: # of trainings conducted; # of factsheets or informational documents distributed

Monitoring: Monthly program reports.

Activity 4: Connect families to transition resources to promote transition to adulthood

Output Measure(s): Number of transition information materials developed and referrals made

Monitoring: Develop informational materials for and referrals made to connect families to transition resources, including P2P e-community resources

Activity 5: Partner with community partners to host a Youth Transition Summit

Output Measure(s): Youth Transition Summit Planned and Completed

Monitoring: Youth Transition Summit contract executed