

Kentucky CSHCN 2013 Maternal Child & Health Application/2011 Annual Report

Each year, all states are required to submit an Application and Annual Report for Federal funds for their Maternal and Child Health Services Title V Block Grants. While the Kentucky Department for Public Health is the Kentucky grantee, federal guidance requires that at least 30% of Title V funding be allocated for services for Children and Youth with Special Health Care Needs (CYSHCN). Services for CYSHCN are administered in Kentucky by the Commission for Children with Special Health Care Needs (CCSHCN) and include providing and promoting family-centered, community-based, coordinated care (including care coordination services) for CYSHCN and facilitating the development of community-based systems of services for such children and their families. This document summarizes the draft application & report of the portion of the Application and Annual Report pertaining to CYSHCN.

Section I Public Input

- CCSHCN seeks input from staff, supervisors, management, and stakeholders in the creation of the Application and Annual Report. Additionally, CCSHCN makes special efforts to reach out to families of CSHCN – including their representatives on the Youth Advisory Council and Parent Advisory Council.
- CCSHCN wants to hear your comments! If you have any comments on this document, or want more information on the 2013 Maternal Child & Health Services Title V Block Grant, please respond electronically via the link on our website, or by visiting: <http://www.surveymonkey.com/s/2013MCH-KYCCSHCN> If you do not have access to a computer, or have any questions, you may contact Mike Weinrauch at (800) 232-1160, ext. 250.

Section II Needs Assessment Summary

- Every 5 years, a formal needs assessment is completed; the current one was submitted in 2010. With input from community stakeholders, CCSHCN decided that the 2 priority needs over the 5 year period would be addressing obesity and provision of transition services for CSHCN. State Performance Measures 7 and 8 (see below) describe Kentucky's plan for addressing these priorities. CCSHCN has convened workgroups for each priority need, and these workgroups meet regularly to monitor progress.
- As assessment is an ongoing process, CCSHCN is continually looking at its services to see what can be improved or fine-tuned. Through information and feedback received through clinic comment cards for children and youth enrolled in CCSHCN, and through the National Survey of Children with Special Health Care Needs (NSCSHCN), CCSHCN is able to identify strengths, as well as needs and gaps, and to assess the current environment. The Kentucky Integrated Services for CYSHCN (KISC) steering committee is a new means to identify and address needs.

Section III Overview

Note: The following sections contain original narratives submitted in 2010, as well as the annual update from last year (marked /2012/), which follow the original submissions. This year's updates appear in **bold** and *italics* and are marked /2013/.

- A – Overview

CCSHCN dates back to 1924 when it was created by the State Legislature in response to a request from the Rotary Club to provide treatment to children with orthopedic conditions through itinerant clinics across the state. The focus on community-based systems of care continues today. In addition to being a direct services provider, CCSHCN assumes a leadership role in assuring state and local systems of care for children and youth with special health care needs (CYSHCN) and in promoting a broader definition of health for CYSHCN and their families as defined by the World Health Organization: "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity."

CCSHCN has a strong commitment to the inclusion of families and family support. This was acknowledged and enhanced in 2009, when CCSHCN was awarded the Family to Family Health Information Center grant, which provides for developing family partnerships throughout the state, so families may act as mentors for each other. As a national leader in developing systems to support the transition of CYSHCN to adulthood, KY became the first state to develop a Title V performance measure for

transition to adulthood in 1997. This initiative has continued to be an area of growth and continues to evolve to meet the needs of our children beginning at enrollment, regardless of age.

CCSHCN continues to focus on the expanded need to serve children statewide, including an increased emphasis on population-based services. The KY Early Hearing Detection and Intervention (EHDI) program consistently reports the screening of over 99% of KY newborns with referrals for diagnostic screening given to all children reported to have a risk factor for hearing loss. The program is currently focused on obtaining the follow-up diagnostic testing results for the newborns who have been identified as at-risk for hearing loss.

/2012/ During the past year, CCSHCN has initiated a thorough examination of the agency's policies and procedures manual in an effort to align to the current environment. Each policy is being reviewed with an eye towards process improvement and better definition of the role and interactions with community partners. At the same time as existing policies are being modernized, several new practices are either proposed or now in effect, most notably with regard to the agency's State Performance Measures - obesity and transitions - more information follows in the narrative for SPMs 7 & 8. /2012//

/2013/ As of 11/1/11, Kentucky moved forward with a new network of 3 statewide Medicaid managed care organizations (MCOs), in addition to the 1 MCO which was already in place in the Louisville area. In an effort to save state funds, the project was implemented at a significantly accelerated pace. This caused access to care issues, as CYSHCN and their families were suddenly faced with navigating an unfamiliar system of managed care. While families now have choices in coverage among the 3 MCOs, finding contracted providers to meet their needs has been a challenge. Providers are upset about payment issues, which may result in provider networks being less robust. Pre-authorizations for medical procedures for which CCSHCN had previously been exempted is also an issue. Due to the large percentage of CYSHCN on Medicaid in our state, this presents an obstacle and this is a tumultuous time for this program.

CCSHCN's foster care support programs continue to remain a vital component of Kentucky's plan to meet the health care needs of children in the child welfare system. Co-located nurse consultants provide consultation to and medical coordination assistance for the child welfare personnel; agency nurses provide home visitation services to medically fragile children in foster care, and CCSHCN and the University of Kentucky jointly operate a medical home clinic operating to serve the needs of children in foster care. These programs predated the federal Fostering Connections to Success Act, and aimed to address system failures in service gaps/fragmentation/duplication. The focus at this time is on data and accountability – quantifying that the collaboration is a success is a goal – continuing what works, and refining what may need improvement.

CCSHCN intends to expand services beyond the relatively small population of CYSHCN traditionally served by the program. During the process of applying for State Implementation Grant/D70 funding, CCSHCN looked at the system of care, particularly with an eye towards improving transition to adult health care providers and assurance of medical home-type environments. Although the life span of CYSHCN continues to increase, adult providers remain unfamiliar with the pediatric histories of CYSHCN presenting as new patients. CCSHCN has been educating CYSHCN but notes a disconnect between what a youth may know and what he/she is able to do, for various reasons. CCSHCN continues to partner with youths to empower them to manage their own care from youth to adulthood. While continuing to educate about barriers, CCSHCN also aims to assist in providers' ability to receive the CYSHCN. CCSHCN's effort to span the gap includes efforts such as the SIG/D70 grant, and the agency's 13-point Transition Action Plan (see SPM 8).

CCSHCN is participating with the state's primary stakeholders to collaborate on

the delivery of health care in a more community-based system of itinerant clinics. There seems to be a philosophical shift among public and private entities toward community-based care and recruitment/retention of medical specialists.

CCSHCN is in the process of strategic planning to guide vision and direction for the next 3-5 years. //2013//

▪ B – Agency Capacity

Despite challenging economic times, the Commission maintains a strong commitment to enhancing the quality of life for KY's children with special health care needs through direct service, leadership, education and collaboration. Through 12 regional offices across the state, direct medical services are provided to children with defined medical conditions, both congenital and acquired. Locations of regional offices and list of conditions treated by CCSHCN can be found at: <http://chfs.ky.gov/ccshcn>. Through diverse staff (nurses, therapists, nutritionists, transition coordinator, social workers, medical director, audiologists, parent liaisons, for example), CCSHCN provides family-centered, community-based care by sending treatment teams including nurses and pediatric specialty physicians to clinic sites throughout the state. Clinics for specific complex conditions that require multi-physician treatment teams are held only in Louisville and Lexington due to availability and coordination of providers.

Throughout the state, alignment with universities and partnerships with other agencies (e.g. Shriner's & Kosair hospitals, Norton Healthcare) support access-to-care issues, lend capacity to the agency, and promote non-duplication of services. Families in need receive financial support to assist with travel and/or lodging in order to attend clinics or receive hospital services. CCSHCN maintains a local provider network through contracts with approximately 600 contract physicians and surgeons. Other medical and ancillary services (e.g. therapists, pharmacists, audiologists) are available through contracts with local community providers. CCSHCN also contracts with foreign and sign-language interpretative services to assure effective communication that is easily understood by families of diverse cultures including those with hearing impairments. These services are available in each Commission region.

CCSHCN has a Memorandum of Agreement with the UK to operate and staff a Medical Home for Coordinated Pediatrics, designed to provide primary health care and other services to the foster care population. CCSHCN also has a Memorandum of Understanding with the Department for Community Based Services (DCBS) to provide nursing consultative services to children in the foster care system. Consultation to the DCBS social workers and foster care families includes discussion of medical issues, interpreting medical records and reports, assuring updated portable health summaries and enhancing care coordination of all services to improve health outcomes for this population.

CCSHCN supports and encourages process improvement with the recommendations of parents of and CYSHCN. In addition to two parent consultants who are on staff, the agency coordinates a Youth Advisory Council which provides an opportunity for CYSHCN to collaborate with other youth, discuss pertinent issues, express needs to CCSHCN staff and become empowered in the management of their own health care. As well, the Parent Advisory Council and provides the same opportunity for parents of children and youth with special health care needs. Council members are provided financial support with their travel, meals, and lodging.

In 2009, CCSHCN received a Family to Family Health Information Center (F2F) grant. This funding provides parent consultants the ability to coordinate family partnerships throughout the state. Although the partnerships will be voluntary, CCSHCN will provide financial support with travel, childcare, meals, and lodging as needed. This new family mentor-matching program will provide a gateway for information-sharing between families, and will allow them to maximize their existing community resources. CCSHCN also received a grant for the KY Infants Sound Start initiative to support the same, as well as support for the KY chapter of Hands and Voices-an organization for families and

children who are deaf or hard of hearing.

CCSHCN continues to expand the capacity of its health information system to fully support the core functions of public health as relates to CYSHCN: to assure early identification and screening leading to diagnosis, treatment, and access to community-based systems of care; to provide comprehensive care coordination with the context of the medical home; to identify and eliminate disparities in health status outcomes; and to support program accountability through the collection, analysis, and reporting of data and progress in meeting performance targets. The electronic patient data collection system (CUP) allows staff to enter patient information directly into a system designed to serve as an electronic medical record. Information pertaining to the demographic, diagnostic, treatment, medication, insurance, and transition history for each patient is maintained in a password-protected system on a secure network. This system is designed with future expansion and accommodation of agency needs in mind. Most recently, enhancements were made which enable audiological follow-up results to be electronically transferred, whereas, in the past, agency staff was manually entering each submitted follow-up report. This will improve the collection of follow-up audiological information; thus reducing the number of children who are lost to follow-up.

CCSHCN is experiencing an expansion of audiology services, and is becoming the preferred pediatric audiology specialist in the state. CCSHCN has more pediatric audiologists than any other public or private agency, provides technical assistance to and participates in partnerships with school systems, serves as a state and national consultant on EHDI issues, and is moving towards cochlear implant support services due to the absence of other providers in this arena.

/2012/Videoconferencing equipment has been procured for several offices. This offers promise in the area of telemedicine; while not realized yet, there has been some use of this technology in staffing difficult cases. CCSHCN has obtained iPads for use by SLPs with patients, as the iPad offers applications for speech and language therapy.

Incorporating an electronic provider dictation/transcription system into the existing data system is pending the purchase of a new server.

CCSHCN has added cochlear implant mapping services and hired a second Dietician to support clinical services as well as the Obesity initiative. The agency now has Dieticians serving the eastern and western regions of the state.

Neurology clinics have been added in the western half of the state to meet a growing need and improve access to care.

CCSHCN and First Steps, the state's early intervention system, have entered into partnerships in the areas of interpreter services and audiology. First Steps now contracts with CCSHCN to utilize its interpreter service network, and CCSHCN is the preferred audiology provider for First Steps. These arrangements improve quality and pathways of communication for referrals, ensure more personal and consistent connections, reduce cost to a sister agency, and increase the opportunity to capture "lost to follow-up" infants/toddlers who do not pass newborn hearing screening.

In addition to the state budget reductions which decreased available state funding by 3.8%, CCSHCN has experienced a loss of \$350,000 for the year due to diminishing and redistributed tobacco settlement funds.

Other issues include the restrictive nature of state contracting and its negative impact on CCSHCN's ability to expand and respond quickly using well-trained outside vendors and specialists, and the state-mandated hiring process which is overly burdensome in its requirements, resulting in delays in filling vacancies or hiring new staff.//2012//

/2013/ All CCSHCN locations now have videoconferencing equipment, which is not only decreases the use of travel time and expense and increases work time, but also is used to maximize involvement and eliminate barriers to participation in the Parent Advisory, Youth Advisory, and Medical Advisory Councils.

iPads have become a vital therapy tool for CCSHCN speech-language pathologists, who incorporate many applications into therapy. Children with communication disorders benefit from the use of creative and motivating “apps” which facilitate progress toward the child’s individual treatment plan. The device is particularly useful for children who are primarily non-verbal due to physical limitations.

CCSHCN is working on wireless access and connectivity in clinics for contracted providers and parent consultants to improve the ability to get resources to families.

A server has been procured and training of physicians and staff is now being organized in an effort to implement an electronic dictation/transcription system.

As part of the State Implementation/D70 grant, and through Kosair Childrens Hospital’s Bridges to the Future transition program, there are now more staff and partners devoting their time and enhancing our ability to identify CYSHCN not currently served by CCSHCN.

Personnel caps and the pay structure in place in state government limits CCSHCN’s capacity to hire workers. A below-market salary range and lack of cost-of-living increases makes recruitment difficult. CCSHCN has experienced extensive turnover.

Family to Family parent mentors now receive stipends for training.

Tobacco settlement funds that have been received for over 10 years and which directly supported audiologist salaries are being totally phased out by 2014. CCSHCN is looking at ways to continue to deliver services across the state. In the audiology field, CCSHCN is now partnering with universities with doctoral programs to receive and train student externs. In the Early Hearing Detection and Intervention program, screening equipment is being placed in regional early intervention point-of-entry offices and health departments in order to increase the capacity to conduct preliminary hearing screening. CCSHCN will be expanding the cochlear implant mapping program in the near future, to provide for equipment and experts in the west (Bowling Green), central (Louisville), and east (Hazard) areas of the state, with plans to continue expansion as the need arises.//2013//

▪ C – Organizational Structure

CCSHCN operates under a streamlined organizational structure, pursuant to a 2009 reorganization. The agency employs an Executive Director; a, Medical Director; 2 Division Directors with one Assistant Director; and a full administrative, support, clinical, and augmentative staff throughout 12 regional offices.

The Division of Administrative Services provides intake, personnel, provider contracting, billing, financial reporting, and health information services. The Division of Clinical and Augmentative Services provides medical and foster care support services, including clinical operations. This division is organized in an East-West structure for clinical programs, and all therapeutic, transition, parent consultant, and audiology services through the Early Hearing Detection and Intervention program are organized under separate managers.

CCSHCN's Executive Director and Division Directors are appointed by the Governor, as are members of the Board of Commissioners and the Hemophilia Advisory Committee – who are stakeholders and interested community members and professionals. The Board of Commissioners provides oversight and approval of the Executive Director's actions. The Board meets quarterly with the Executive Director and senior management to review program status, consult and advise on programmatic concerns, and take

voting action as required. The Medical Director recruits and recommends physicians to serve in clinics and on the Medical Advisory Committee, and the Executive Director, with approval of the Board of Commissioners, appoints members to the Medical Advisory Committee. The Early Hearing Detection and Intervention (EHDI) program also operates under the oversight of the EHDI Advisory Board.

In addition to two contracted parent consultants, the agency incorporates public parent and youth involvement in decisions that impact programs and service delivery. The Parent Advisory Council and Youth Advisory Council are comprised of individuals throughout the state (not just families with children enrolled in CSHCN services) who hold an interest in children and youths with special health care needs (CYSHCN). Each Council meets quarterly at CSHCN's Louisville office (or via videoconference) to discuss pertinent issues, provide training and give input on how CSHCN can better serve Kentucky families with CYSHCN.

//2012/CSHCN has been without a full-time Executive Director since 9/1/10, and is experiencing difficulty recruiting qualified candidates//2012//

//2013/ After a transitional year without a full-time Executive Director, Gov. Beshear appointed Jackie Richardson to lead CSHCN from 9/1/11.//2013//

▪ D – Other Maternal & Child Health (MCH) Capacity

In 2008, the Commonwealth of Kentucky experienced widespread retirement as a result of a designated retirement window. The Commission for Children with Special Health Care Needs (CSHCN) was impacted as well.

Executive Director - Rebecca Cecil, R. Ph., served as CSHCN's Executive Director from 2008 to 2010. Ms. Cecil served as CSHCN's Director of Health and Development immediately prior to her appointment. [Her position was open from 9/1/10 through 9/1/11, at which time she was replaced by Jackie Richardson.]

Medical Director - Richard McChane, MD, has served as CSHCN's Medical Director since March, 2007. Dr. McChane is also the Medical Director of the Home of the Innocents (a private child caring facility serving children with special needs in Louisville), serves as a developmental pediatrician at the University of Louisville Weisskopf Child Evaluation Center, and is a faculty member with the University of Louisville School of Medicine - Department of Pediatrics.

Director of the Division of Administrative Services - Shelley Meredith has served as director of this division since October 2008. Ms. Meredith has over 25 years experience with state government, over 20 of which have been with the Cabinet for Health and Family Services in the health care arena. Ms. Meredith played a key role in the establishment and development of the CSHCN's health information system and electronic medical record and is now responsible for managing all the operational functions of CSHCN including budgets, contracts, purchasing, accounts payable and receivable, health information and technology, personnel, and grant reporting. Ms. Meredith is a Certified Public Accountant and 1985 graduate of the University of Kentucky with a BS in Accounting and a minor in Economics.

Director of Clinical & Augmentative Services - Anne Swinford has served as director of this division since 2005. Ms. Swinford's previous experience includes the provision of direct speech and language services to the special needs population, and served as the Acting Part C Coordinator and supervisor of Kentucky's early intervention program (First Steps). Ms. Swinford has over 25 years experience with special needs populations, including 17 in Kentucky's Cabinet for Health and Family Services. Ms. Swinford is a graduate of Brescia University and Purdue University, where she earned a BA in Speech and Hearing and a MS in Speech Pathology.

Assistant Director of Clinical & Augmentative Services – As assistant director, Karen Rundall functions as CSHCN's Director of Nursing. Ms. Rundall has served in this role

since 2009. Ms. Rundall has over 22 years of experience as a registered nurse providing pediatric care for children with special needs, including 9 years at CSHCN as a care coordinator and nurse service administrator. Ms. Rundall is a certified case manager (CCM) and a graduate of Jefferson Community College (ADN) and Bellarmine University (BSN), both of which have contracted with her to teach pediatric clinical experience at Kosair Children's Hospital. She also holds an MSN in Healthcare Leadership and Management from Western Governor's University.

Title V MCH Block Grant Coordinator - Mike Weinrauch serves as CSHCN's Title V coordinator. Other areas of focus include technical assistance with foster care support programs, social work with the bleeding disorder population, guidance to staff on brokering community resources, and general policy analysis/program evaluation. Prior to employment with CSHCN, Mr. Weinrauch served in Kentucky's child welfare & adult protective services agency as a field worker/supervisor and administrator at the regional and state levels. Mr. Weinrauch is a graduate of the University of Vermont (BA), the University of Kentucky (MSW), and the University of Louisville (MPA).

//2012/Effective 9/1/2010, Rebecca Cecil retired as Executive Director and has not yet been replaced by a full-time appointee. The Cabinet for Health & Family Services Deputy Secretary (and previous CSHCN Executive Director), Eric Friedlander is serving part-time as Acting Executive Director, until such time as a full-time replacement is appointed..//2012//

//2013/ Effective 9/1/2011, Jackie Richardson was appointed Executive Director. Ms. Richardson served 18 years with the Louisville Metro Government in various roles. Her career encompasses experience as an Internal Auditor, Business Manager, Chief Financial Officer and most recently 4 years serving as the Chief of Staff for the Louisville Metro Department of Public Health and Wellness. Mrs. Richardson possesses a Masters in Business Administration and a certification as a Professional in Human Resources.//2013//

▪ E – State Agency Coordination

CSHCN has a Memorandum of Agreement (MOA) with the Department for Medicaid Services that enables the agency to provide services for Medicaid eligible children enrolled for Title V/CYSHCN services. This agreement assures that services are provided in accordance with the Title XIX State Plan and EPSDT special services as required by OBRA 89.

CSHCN also operates under a Memorandum of Understanding (MOU) with the Department for Community Based Services (DCBS) and is providing nursing consultative services in 8 of the 9 DCBS regions for children in the foster care system. This program was initiated in February 2005 to provide services for children who are medically fragile. It was expanded statewide in July 2006 to include the entire foster care population. The Nurse Consultants who work with this program provide consultation to the DCBS social workers and foster care families on medical issues, interpret medical records and reports, assure updated portable health summaries and enhance care coordination of all services. In November, 2007, it was further expanded in a collaborative effort with the University of Kentucky to open (via a separate Memorandum of Agreement) the Medical Home for Coordinated Pediatrics in the Lexington office, which provides primary care services to children in foster care in the central region of the state.

The Early Hearing Detection and Intervention (EHDI) program maintains many relationships in the administration of Kentucky's legislatively mandated newborn hearing screening program. In addition to the partnerships with the state's birthing hospitals, the program collaborates with the Commission on the Deaf and Hard of Hearing and the Kentucky chapter of Hands and Voices. Since 2006, a partnership with Vital Statistics has allowed the program to receive newborn hearing screening results for every child born in Kentucky electronically through the KY-CHILD database. Ongoing efforts at this time include work to expand online data transmission to allow community audiologists

and early interventionists to electronically transmit diagnostic assessment results and to the EHDI program. New efforts are focused on working with Part C leaders to further expand Early Intervention services that more effectively meet the specific needs of newborns diagnosed with permanent hearing loss. In March 2009, Governor Beshear signed HB 5 which requires audiology diagnostic sites who wish to be included as approved centers for pediatric audiological testing to agree to meet specific requirements, including best practice standards and reporting to the EHDI program.

An agency partnership with Home of the Innocents (a private child caring agency providing hospital-like and "home away from home" environments for medically fragile children) allows Louisville therapeutic staff (PT, OT, SLP) to reside and provide services at the Home of the Innocents facility. This arrangement allows CCSHCN patients and staff to utilize the advantages of a new facility, with state-of-the-art equipment, that is closer to the downtown area & medical complexes.

Memoranda of Agreements are maintained with the University of Kentucky and the University of Louisville to provide Hemophilia Treatment Centers covering the entire state's bleeding disorder population. CCSHCN also provides assessments for the state's Disability Determinations Services division on behalf of the Social Security Administration for residents of Kentucky.

Currently, CCSHCN is working towards Memoranda of Agreement with First Steps to provide audiological services and to improve and streamline interpretation services. CCSHCN collaborates with the Kentucky Council on Developmental Disabilities (KCDD). The mission of the Kentucky Council on Developmental Disabilities is to create change through visionary leadership and advocacy so that people have choices and control over their own lives.

CCSHCN maintains numerous additional relationships with other state agencies. Programs with which our agency collaborates include: local schools, Office of Vocational Rehabilitation, Special Needs Adoption Program, the Kentucky Community & Technical College System, local health departments, Family Resource Youth Service Centers, Regional Interagency Transition Teams (RITT), State Early Childhood Transition Committee, KIDS NOW, State Interagency Council on Services to Youths with Severe Emotional Disabilities, and the state Child Fatality Review Program. Agency association with these entities allows us to further develop goals for the agency, provide community training, streamline services for children with special health care needs in their community and schools, educate, as well as prepare children for the transition into adulthood.

/2012/ CCSHCN now provides nursing consultation statewide, in 9 of 9 DCBS service regions.

CCSHCN has initiated a program that allows families of children with permanent hearing loss to be partnered with parents in the Hands and Voices group to help these families navigate the system of care for deaf/hard of hearing infants and children. The mentor parents assist families in an unbiased way to make decisions that are appropriate for their family with regard to communication mode, intervention services, and providers.

CCSHCN has signed Memoranda of Agreement with First Steps to provide audiological services and is administering their interpreter services.

CCSHCN looks forward to the possibility of coordinating with DPH's MCH epidemiologist, who (pending grant funding) will work onsite directly with CCSHCN staff on a biweekly basis to assist in program evaluation, analysis of MCH data, data linkage projects as well as joint special projects.

CCSHCN has been collaborating with the Kentucky Department of Education to follow up on school scoliosis screening programs and hearing conservation programs. Working toward building a stronger relationship in the near future. Under Kentucky law, schools have the responsibility to screen, while CCSHCN is to provide guidance through consultations and resources for the implementation of the screening programs

	<p>and subsequently as a direct service provider to children who fail these screenings at school.</p> <p>CCSHCN was awarded a State Implementation Grant and will begin working with the Kosair Children's Hospital's Bridges to the Future transition program and would also like to extend collaborative programs to the eastern part of the state by partnering with the University of Kentucky. To fulfill an additional objective for this grant, CCSHCN also hopes to develop partnerships with community free health clinics for uninsured patients and to provide family/professional support for Hispanic families without insurance coverage. //2012//</p> <p>/2013/ CCSHCN's information system now contains a designation indicating whether a child is receiving Kentucky's Part C Early Intervention Services, or "First Steps".</p> <p>The State Implementation Grant/D70 partnership has convened a steering committee comprised of internal and external stakeholders and representatives from professional groups and families to direct the activities of the grant. CCSHCN is collaborating with Kosair Children's Hospital's Bridges to the Future transition program to expand transition services to children outside the CCSHCN program. This program provides a portable health record and transition resources to enrollees and their families, and will be instrumental in developing a register of physicians committed to serving transition-age CYSHCN as they become adults. Proposed grant activities include a weekend transition retreat, transition day workshops, school transition fairs, a parent collaborative, physician referral resource, and patient/physician portals to the electronic health record. At this time, CCSHCN has put on hold plans to provide family/professional support for Hispanic families without insurance coverage – pending the employment of part-time parent consultants.</p> <p>As administration of the Medicaid program switches over to the new managed care organizations (MCOs), new contracts, adjustments to processes will have to be made to ensure that funding remains stable. CCSCHN is collaborating with MCOs to provide care coordination for CYSHCN who are enrolled in the CCSHCN program; to expand provider networks; and to improve identification of CYSHCN and referrals.</p> <p>CCSHCN is working with community partners to investigate gaps or duplication of services and addressing its role in new areas, such as sickle cell, autism, and behavioral health.</p> <p>To promote public-private partnership and in an effort to use newly-developed community resources in an efficient way, CCSHCN is looking for additional opportunities to collaborate with the Home of the Innocents, given their recently expanded capacity to serve, especially in the areas of dental and pharmacy. Home of the Innocents is a prominent leader in providing specialized care to CYSHCN from across the state and to children involved in the child welfare system.</p>
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<p>Section IV Priorities, Performance and Program Activities</p>	<ul style="list-style-type: none"> ▪ National Performance Measures (NPMs) are measurements of results or achievements on specific outcomes. There are 18 common NPMs that all states report on yearly. ▪ State Performance Measures (SPMs) are additional measures selected by Kentucky based on identified priorities and our own unique needs. There are 8 Kentucky-specific SPMs. ▪ CCSHCN has responsibility for reporting on 6 NPMs and 2 SPMs, which are detailed in the sections below.
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<p>National Performance Measure 2:</p>	<p>(Data derived by averaging responses to 2 questions on CCSHCN clinic comment cards, 1 regarding customer satisfaction and 1 regarding partnership)</p> <ul style="list-style-type: none"> ▪ This year's indicator: 97%
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The % of CSHCN age 0-18 years whose families partner in decision making at all levels and are satisfied with the services they receive

▪ **Last year's indicator: 96.8%**

▪ **Last Year's Accomplishments:**

While Kentucky uses state-generated data to report progress on this National Performance Measure, CSHCN notes that in the 2009/2010 National Survey of Children with Special Health Care Needs (NSCSHCN), Kentucky's families reported being partners in shared decision-making at a higher level (73.6%) than the national average (70.3%). This was also the case in the previous survey (2005/2006). Among CSHCN enrollees, satisfaction and family participation remains high.

Through care coordination, CSHCN staff assist and enable CYSHCN to obtain family-centered, culturally-sensitive, developmentally-appropriate services. Staff actively engage in a partnership with families and providers to individualize care, provide support, and obtain the best possible outcomes. To measure the effectiveness of this collaboration and the direct care experience, the agency continued to use a structured comment card protocol in all onsite clinics. The comment cards provide instant and timely input from families on an ongoing basis. The "mini-survey" is comprised of 5 questions (intentionally kept brief to encourage participation), but two separate questions measure satisfaction and listening – a key element of partnership. The resulting numbers are averaged to obtain the annual indicator for the Performance Measure.

Past the direct service level, CSHCN strives to weave the voices of both parents and CYSHCN into the fabric of operations, so that families are involved in policy decisions that affect them, and are partners in decisionmaking. The Parent Advisory Council (PAC) continued to be a vital and relevant group, providing input on a variety of CSHCN matters, and guidance for the KY Family to Family Health Information Centers (F2F). During the past year, topics of PAC discussion included development of a parent tipsheet on requesting educational accommodations, the CSHCN comment card survey, and discussion topics for the agency Facebook page. The tipsheet represents a companion piece to one developed during the previous year by members of the Youth Advisory Council (YAC). YAC continued to meet regularly and, outside of meetings, some YAC members participated in CSHCN activities (such as the Louisville regional holiday party for patients and families), and, as a result of an article published in the statewide transitions newsletter, the chair presented about transition at the Kentucky Department of Education Summer Awards Brunch (audience: high school teachers and college disability coordinators), a presentation which was well-received. YAC members provided input on a variety of CSHCN matters, such as those pertaining to agency efforts to improve transition services for youth (see SPM #8). This feedback has directly impacted service delivery.

Family consultants attended multiple trainings and CSHCN staff participated in community events (e.g. Transition Fairs), partnering with professionals and parents and providing opportunities to take back information on available services to CSHCN patients, and to educate on CSHCN services available to the community. Family consultants played active roles on internal CSHCN work groups (e.g. Healthy Weight and Transition Action Plan) and external committees (e.g. Regional Interagency Transition Teams), lending a family perspective to policy-makers. Family consultants and "family scholars" attended the AMCHP/Family Voices conferences in order to acquire valuable information about national trends in maternal and child health topics and build relevant skills.

Under the guidance F2F, parents provided one on one assistance to nearly 1200 families and over 130 professionals during the reporting period to build the capacity of parents to advocate for their children's needs. 93.5% of families surveyed by Family to Family reported that the assistance/information/resources received was useful in helping them work with professionals to make decisions about their child's health care. Key Family to Family activities included:

- Incorporation of youth volunteers who have special health care needs themselves as mentors. These youths and young adults work in CSHCN

clinics and talk to CYSHCN about their own experiences and what they have learned about overcoming challenges. They also help with identifying helpful resources available to families;

- Development of resource material on topical issues such as the Affordable Care Act, special education, special needs trusts, Early Periodic Screening Diagnosis & Treatment, Medicaid waivers (fliers and bookmarks), accessing durable medical equipment, and “504” plans.
- Participation in the Region 4 Genetic Collaborative and National Coordinating Center for Regional Genetic and Newborn Screening Service Collaborative for Medical Home which produces materials for families and professionals to help them understand and communicate the concept of the Medical Home.
- Facilitation of regional focus groups to assess and determine what families are interested in learning about.

▪ **Current Activities:**

CCSHCN evaluates services provided based on the clinic comment cards and refines as needed. It is the intention of the agency, through its policies and practices, to encourage families to discuss with care coordinators and contracted providers their child’s treatment and to provide a friendly environment in which it is easy to ask questions or raise concerns.

Given that the chief complaint has been a long wait time to see physicians, the agency has begun an analysis of clinic and scheduling processes to determine an appropriate scheduling model that will maintain physician utilization while decreasing the patient’s wait time for services. An in-depth study of one clinic utilized quantitative and qualitative data to determine the length of service intervals and the time patients wait before and between services. Information regarding patient punctuality and probability of no-shows was included in this study. The interaction of these variables were tested against various appointment and sequencing rules to create simulated models that demonstrated how clinic environmental characteristics interact with various scheduling rules to determine the optimal scheduling model intended to decrease patient and physician waiting time. Two offices are currently implementing new appointment scheduling systems based on this type of data and information on their unique clinic environmental characteristics. Patient concerns on the clinic surveys regarding wait times have started to decrease.

Transition surveys, developed with the assistance of both the PAC and YAC, are now available to youths turning 14, 16, and 18 years old and their parents. The surveys intend to measure the CYSHCN’s knowledge (and/or their parent’s perception of the youth’s knowledge) in a variety of transition areas and the responses help CCSHCN know how to help make the child’s transition into adulthood a smooth one. Responses ideally will tell the agency which specific areas of services need to be enhanced for CCSHCN families. Given the low response rate during the first few months of implementation, the project is being reworked and redesigned to encourage better participation – not only from CCSHCN enrollees, but also from CYSHCN not affiliated with CCSHCN. Additionally, the YAC has made a recommendation that CCSHCN nurses develop 1-page educational handouts on specific diagnoses that CCSHCN serves, as a guide for CYSHCN to describe their disabilities to others. The handouts are being reviewed and revised and the YAC looks forward to providing input toward finalized products.

CCSHCN has created a Facebook page to expand and improve communication with current clients and provide outreach to unserved CYSHCN through social media. Updates are more frequent than in years past; however, communication still appears to be mostly a one-way affair. With more publicity and familiarity, it is hoped that a more interactive relationship with CYSHCN may be cultivated.

Current activities for F2F include expanding the network of parent consultants and working with families and professionals directly to assist in problem-solving, other current Family to Family activities include the facilitation of further focus groups across the state to gauge the needs of parents. Family to Family staff continue to send packets of informational resources to parents of newly-diagnosed infants with permanent

	<p>hearing loss and make follow-up calls to offer assistance. Co-directors have also been instrumental in orienting CSHCN's new State Implementation Grant administrator to the family experience.</p> <ul style="list-style-type: none"> ▪ Plan for the Coming Year: <p>CCSHCN relies on its Board of Commissioners, PAC and YAC for guidance on how to best address the concerns of the special needs population. Board members are often parents of special needs children or practitioners with extensive expertise treating this population, including early intervention, the Kentucky Deaf-Blind Project, and a protection/advocacy program for the disabled. Such diversity allows CSHCN to receive feedback from a variety of external sources regarding the public perception of CSHCN programs.</p> <p>CCSHCN will continue to enhance and improve relationships with managed care organizations, and identify access to care issues for CYSHCN population in Kentucky.</p> <p>CCSHCN will continue to monitor results of surveys to ensure continued satisfaction among families of CYSHCN.</p> <p>Through the strategic planning process and activities of the State Implementation/D70 grant, CSHCN will research ways to impact CYSHCN who do not currently receive services from CSHCN.</p>
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<p style="text-align: center;">National Performance Measure 3:</p> <p style="text-align: center;">The % of CSHCN age 0-18 years who receive coordinated, ongoing, comprehensive care within a medical home</p>	<p>(Data derived by dividing CSHCN patients 0-18 who identify a primary care physician by total population of CSHCN patients 0-18)</p> <ul style="list-style-type: none"> ▪ This year's indicator: 93.7% ▪ Last year's indicator: 93.6% <ul style="list-style-type: none"> ▪ Last Year's Accomplishments: <p>The Medical Home for Coordinated Pediatrics (MHCP), a collaboration with the University of Kentucky and housed in the Lexington CSHCN office, continues to provide primary care and care coordination for children involved with Kentucky's child welfare system. Enrollment during the reporting period continued to increase significantly (almost 1700 visits during the reporting year, up from 1300 the previous year).The program is a well established part of CSHCN's array of services.</p> <p>Staff participate with the Region 4 Genetics Collaborative which has a core mission to assure that CYSHCN receive comprehensive care in a medical home environment. Through collaboration with Region 4, informational handouts and guides have been obtained and incorporated in the family consultants' educational resources to ensure families become familiar with the principles of the medical home through a variety of methods. CYSHCN families are educated about what a medical home offers accessible, continuous, comprehensive, coordinated, compassionate, and culturally effective family centered care. Tip sheets are also available to provide guidance regarding choosing and working with a doctor, preparing for and participating in a doctor's appointment, what care coordination and culturally effective care look like, as well as continuous care while transitioning to adult care.</p> <p>As is mentioned elsewhere, Kentucky received and began work in earnest on a State Implementation/D70 grant which has as a goal of developing partnerships to ensure that CYSHCN have the resources and assistance needed for ongoing comprehensive care within a medical home. CSHCN has convened a steering committee of partners (including the American Academy of Pediatrics Kentucky Chapter medical home champion) charged with overseeing these activities. Impacts desired include outreach to previously unidentified CYSHCN, a self-sustaining comprehensive transition model, and access to resources that assist CYSHCN in becoming active partners who transition successfully into adult medical homes.</p> <ul style="list-style-type: none"> ▪ Current Activities: <p>Twelve CSHCN offices throughout the state continue to provide on-site multidisciplinary specialty clinics. CSHCN strives to ensure that all patients are active</p>
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with a primary care physician by verifying that primary care services are received at each clinic encounter. If primary care is not identified, the clinical staff attempts to connect the family with an appropriate provider within its community. To ensure continuity of care, specialty clinic dictation and medical plans of care are shared with the patient's primary care physician in accordance with HIPAA guidelines after each clinic visit.

CCSHCN registered nurses and social workers provide comprehensive care coordination. These services include education, and developmentally appropriate transition services mindful of lifelong health goals and uninterrupted services into adulthood.

The medical home model is difficult to provide in a single setting. The CCSHCN foster care program continues to collaborate with the Department for Community Based Services (child welfare agency) to support the medical home model by ensuring that ongoing, preventative health services are addressed for the foster care population and those at risk of placement in foster care. Nurse consultants integrate into practice an assessment and communicate with social services workers about the need for a medical home on all consults completed. Nurse consultants support the medical home concept by providing health education to youth, foster parents, and social service workers, as well as facilitate referrals to pediatric and specialty health care.

CCSHCN administrative staff have revised an assessment tool that focuses on youth aged 14 through 18 years to assure access to resources that provide a continuous comprehensive system of health care into adulthood upon implementation. Each patient receives a birthday letter at age 14, 16, and 18 that discusses future needs and invites the youth to contact his or her care coordinator to find services and to better prepare the youth for the transition into adult care systems. The questionnaire also identifies the patient and families progress toward this transition.

▪ **Plan for the Coming Year:**

CCSHCN staff continue to work with families to ensure that CYSHCN have medical home-type environments. A further emphasis on follow-up is planned on referrals. As standards of practice are established for care coordination, clinical staff will receive education to enhance and support their role in the medical home model. Further, cultural competence awareness is being organized to provide a more culturally aware workforce.

One of the objectives of the State Implementation/D70 grant (Kentucky Integrated Services for CYSHCN, or "KISC") is implementing the Medical Home concept. In conjunction with the KISC Steering Committee and Kosair Children's Hospital Bridges to the Future transition program, CCSHCN is actively working on workshops and community outreach to educate physicians who are unfamiliar with the Medical Home concept. As KISC moves forward, CCSHCN is working to build a network of adult physicians committed to providing care to transition age CYSHCN to improve the access of care as CYSHCN move to an adult health care model. KISC is conducting outreach to encourage adult providers to embrace the medical home concept. CCSHCN's development of a physician portal will enhance the referral pathways for participating physicians as well increase access to quality and comprehensive care for CYSHCN.

National Performance Measure 4:

The % of CSHCN age 0-18 years whose families have adequate private and/or public insurance to pay for the services they need

(Data derived by dividing CCSHCN patients 0-18 with private or public insurance by total population of CCSHCN patients 0-18)

- **This year's indicator: 95.7%**
- **Last year's indicator: 95.8%**

▪ **Last Year's Accomplishments:**

CCSHCN has continued to maintain a low uninsured rate by moving to a centralized approach of financial eligibility processing with a team who specializes in this function. Insurance status continues to be verified on patients who are scheduled for upcoming services but now when a lapse in insurance is identified, the Intake and Eligibility Branch is immediately notified and steps are promptly initiated to restore coverage.

Undocumented aliens, Amish and young adults who are out of school and are over the age of 18 years old, continued to represent the majority of the uninsured population served. CCSHCN provided financial support and assistance for high cost conditions and low income populations to reduce barriers and ensure that needed services were acquired in a timely fashion. CCSHCN social work staff have become proficient in advocating and securing temporary Medicaid coverage for those undocumented aliens requiring surgeries which prevent future medical deficits and/or emergencies resulting from the lack of needed treatment.

Through a partnership with Patient Services Inc. (PSI), CCSHCN was able to continue the provision of insurance case management for hemophilia and cystic fibrosis patients who are over the age of 18 and are uninsured or at risk of losing their insurance coverage. A review of the process was conducted to identify, 1) how long the process took from point of referral to the securing private insurance, 2) what the reasons were for patients not completing the process of securing insurance coverage, and 3) what adjustments could be made to make the program more successful.

As a result of our review and findings, we removed the initial financial barrier to application and incorporated the special application required for this program into our centralized intake and eligibility process and made it a requirement for participation. This team, through their contact and relationship with patient, counsels about the financial benefits, familiarizes the patient with the partnership, and ensures the application is correctly completed. Once received, they directly submit the information to PSI for processing. CCSHCN also implemented a feedback loop so that additional intervention and assistance could be provided should the need arise. There was a slight increase in the numbers who gained assistance with health insurance but we hope to improve this further.

The expansion of the Medicaid managed care system in Kentucky, from one to four (4) organizations in the fall of 2011 has had a dramatic impact on the provision of care for CYSHCN. Approximately 15 – 20% of Kentucky's total Medicaid population, which resides in the sixteen (16) counties surrounding the Louisville metropolitan area, has been served by a managed care organization (MCO) which was originally created as a partnership by local stakeholders. The statewide expansion, which was bid out, awarded and executed in just over 6 months, currently lacks the breadth of contracted specialty providers required and willing to serve the population of CYSHCN. CCSHCN has entered into contracts with each MCO and has been working with and advising them on the obstacles we are encountering with service delivery.

Providers have expressed concern over contracting language, reimbursement rates, prior authorization requirements and increased overhead costs. Consumers have experienced confusion and frustration when the providers with whom they are currently connected are not participating with their newly assigned networks. Much CCSHCN staff time is spent navigating separate and unique MCO rules, forms, and networks, attempting to assure that CYSHCN receive authorized services they need from covered providers who participate in their networks. Educating patients and families on the new requirements and intricacies of their new insurance plans has made care coordination in this environment a real challenge.

▪ **Current Activities:**

CCSHCN staff have had to become experts in patching together coverage for CYSHCN in various gaps and recognize that there are no one-size-fits-all insurance solutions. CCSHCN is investigating how to maximize utilization of the Kentucky's pre-existing condition insurance plan (PCIP). PSI has been successful in accessing this resource for the designated pool of patients they support but CCSHCN is looking for additional ways to identify and assist others who may be eligible. Kentucky's PCIP enrollment has been steadily increasing during the reporting year and has been helpful to many waiting for key provisions of the Affordable Care Act to go into effect. A state-administered high-risk pool also exists but the cost for these plans are often prohibitive, while the PCIP rates are very reasonable.

CCSHCN has sought out and found community partners who are serving the needs of the uninsured and have begun discussions on how we might work coordinate our activities to support these patients and families. We hope to accomplish this through staff education, referrals and parent advocates.

▪ **Plan for the Coming Year:**

For the population of uninsured CYSHCN 18-21, the State Implementation/D70 grant team will be developing a plan for providing health care resources, and distributing helpful resources to this population. CCSHCN will be keeping apprised of new developments and information regarding federal health care reform and the implications for CYSHCN. In addition to traditional methods of dissemination of resources, a greater emphasis on using social media, particularly through CCSHCN's Facebook page, is planned, so that more stakeholders may be educated about solutions that may be available.

As CCSHCN continues to make efforts to push down low uninsured rates for patients where public insurance is an option, it recognizes that there are still pockets particularly related to underinsurance. The current trend is a shift of financial risk and burden of health care from the insurance carrier to the subscribers has resulted in a significant number of people who are underinsured. With increased deductibles and co-insurance amounts, they simply do not have the additional financial resources, over and above the premium costs, to pay the rising costs required for treatment. The insurance plans are shifting from having set, moderate, easy-to-anticipate copayment amounts towards high deductible plans (HDPs) and co-insurance percentages with very high splits; some of them moving as high as 50-50%.

Quantifying benefit levels poses quite a challenge due to the sheer number of plan offerings and the variety of nuances contained in each. Finding a methodology for setting criteria to measure and assess the level of underinsurance will be the challenge for this next year. Once the extent of this barrier is defined, CCSHCN will evaluate how to interface to ensure that timely medical care and interventions occur. CCSHCN intends to establish criteria for measuring the extent of need for those with insurance and then make projections about the programs ability to offer financial and community support to those most in need. Exploration of greater use of Medicaid waiver programs for very medically involved patients may be in order.

CCSHCN will be continuing its efforts to solidify relationships and opportunities with community partners through formalized Memoranda of Understanding/Agreement.

National Performance Measure 5:

The % of CSHCN age 0-18 years whose families report the community-based service systems are organized so they can use them easily

(Data derived by dividing CCSHCN patients 0-18 with recorded note types of "general", "care coordination", "financial", "transitions", "clinic", or "intake" by total population of CCSHCN patients 0-18)

- **This year's indicator: 96.4%**
- **Last year's indicator: 97.4%**

▪ **Last Year's Accomplishments:**

Despite the fact that ease of use of community based service systems represented a strength for the state in the previous needs assessment, results of the 2009/2010 National Survey of Children with Special Health Care Needs showed that 36.2% of Kentucky CYSHCN did not meet criteria for MCHB Outcome 5 – i.e., they reported difficulties or frustration in obtaining community based services that are easy to use. This represents a figure slightly above the national average of 34.9%. In keeping with the practice of several years, CCSHCN reports progress on this indicator with state data – specifically, information on coordinated services received by CYSHCN enrolled in the CCSHCN program. While the numbers remain high, they do not meet the annual objective. No matter how the performance measure is quantified, CCSHCN recognizes that facilitating a more integrated service system is an important goal.

Kentucky's CCSHCN traditional program fills a gap in direct health services by providing specialty clinics in regional offices across the state and recruiting recruiting a network of

contracted providers who are willing to see and treat CYSHCN. Beyond the provision of medical services, though, CSHCN staff assist families of CYSHCN to navigate existing systems of care in many ways – through the care coordination of registered nurses, brokering of services by social workers, nursing consultation by staff outstationed in child welfare offices (see below), and referrals/services provided by a variety of augmentative staff. CSHCN administration works to advance integrated care systems for CYSHCN through collaborations exploring interagency partnerships, and by maintaining an intranet site designed to educate staff about community resources which can assist families. CSHCN also maintains an internet and a Facebook site, which are used to provide information.

The Kentucky Family to Family Health Information Centers (F2F) represent a key strategy toward assisting with education, accessibility of services, and navigation of community based services. During the reporting period, F2F continued to work one on one with families to educate as to how community based services are organized and how they can be accessed. Family to Family also worked with those who were interested in improving the delivery of services by equipping them with the tools and information they needed to advocate for needed changes. During the reporting period, Family to Family engaged almost 1300 families on resources available based on families' needs. Significantly, when measuring impact, 96.7% of families surveyed by Family to Family about their interactions reported that the support/information/resources received was helpful in building family confidence in getting their child the health care and services he/she needs. 83.9% felt that the assistance/information/resources was useful in helping the family find and/or learn about community services. In addition to guiding individual families to services through a network of parent mentors and youth volunteers, Family to Family worked with other entities (such as Kentucky Special Parent Involvement Network and the Kentucky Commission on the Deaf and Hard of Hearing) to increase their expertise in specific services and resources available and then disseminate information. Support parents have attended conferences, workshops, and school events throughout the state to disseminate information with families of CYSHCN, including those enrolled in CSHCN and those outside CSHCN.

CSHCN seeks to collaborate with other community partnerships to coordinate activities and service delivery. CSHCN staff continued to be actively involved in the Kentucky Interagency Transition Council for Persons with Disabilities and 11 Regional Interagency Transition Teams (RITTs) across the state. Participation in these and similar activities enable CSHCN to connect and share information with CYSHCN, their families, and other service providers. CSHCN strives to be a visible and relevant contributor to the local and state service systems and, to that end, last year participated in a variety of multidisciplinary groups, such as Community Collaborations for Children, Safe Kids Coalitions, District Early Intervention Councils and local committees that support area charities and resources for low-income residents.

CSHCN's Foster Care Support program provides individualized assistance through case-specific consultations with the child welfare staff, visits to "medically fragile" children in foster care, and primary care at the Medical Home for Coordinated Pediatrics. A goal of these programs is to make the health care system more navigable for CYSHCN in or at risk of state's care, child welfare workers and foster parents.

▪ **Current Activities:**

Ease of use is currently being significantly affected by new Medicaid managed care organizations' (MCOs) delay of payments – which impacts each MCO provider base and networks.

It is a goal of CSHCN to ensure that all CYSHCN, not just CSHCN enrollees, have access to medical providers and coordinated support services that they need. As such, the agency has begun to gather and examine where in the state CYSHCN reside based on prevalence and incidence rates and other data being reported by partner agencies/organizations who serve these populations, and how more can be reached – whether by CSHCN or other providers. Staff involved in needs assessment activities are gathering demographic data, while CSHCN leadership are communicating with other providers and planning ways to better outreach to large concentrations of

CYSHCN. Staff moves forward toward the objectives of the State Implementation/D70 grant, which includes developing partnerships to ensure CYSHCN have the resources and assistance needed for care and support. Representatives from several major healthcare organizations are contributing their time to the project's steering committee. The Bridges to the Future program, funded by the grant and administered by the Kosair Children's Hospital, marks a key community partnership in which services are available to CYSHCN not served by CCSHCN. Wherever and whenever it can, CCSHCN endeavors to provide infrastructure support to other service providers, in an attempt to integrate services in a way that makes them accessible to all, and connect CYSHCN with resources. Using an Early Childhood Access Guide developed by the Kentucky Partnership for Families and Children and the Early Childhood Family Network Committee, CCSHCN staff in every office help families navigate and connect to available resources.

CCSHCN is identifying and reconnecting with common partners to define our collective roles and contributions toward improving the infrastructure for this target population. For example, contact has been made with the Kentucky Department of Education regarding hearing screenings and scoliosis screenings, and with First Steps (Kentucky's early intervention system) regarding referral patterns, enrollment qualifications, and service provision.

CCSHCN is working with the Youth Advisory Council (YAC) & Parent Advisory Council (PAC) in an effort to improve the CCSHCN Facebook page by eliciting more activity and posting relevant discussion topics of interest. The development of social media has evolved slowly, yet efforts continue.

In addition to employing care coordinators, social workers, and family consultants who consult, advise, and refer families, CCSHCN maintains and monitors a dedicated consumer call line, through which CCSHCN enrollees or members of the general public may be connected with a service or resource or be assisted with an issue. While a relatively small number of calls come in, this represents one additional avenue that Kentucky has established toward connecting CYSHCN with services for optimal outcomes.

▪ **Plan for the Coming Year:**

CCSHCN is considering adjusting data collection efforts to better measure ease of use of community based services for CYSHCN. Technical assistance may be requested on how to improve collection efforts so that the agency ensures validity in measuring and reporting on this NPM.

CCSHCN's F2F will continue to work with families and seek their input on their needs and provide training to assist, and will develop additional materials that are easy for families to understand regarding how to navigate community based services. F2F is now seeking advanced matching software.

As part of the agency transition plan (see SPM 8), CCSHCN will be working to improve how it acquaints patients and their family members with community based services to help make it easier for families to access these services.

As the recipient of a State Implementation Grant for Systems of Services for Children and Youth with Special Health Care Needs, CCSHCN has as objectives working with community partners and building relationships to minimize duplication of effort while improving outcomes for CYSHCN. CCSHCN continues to add providers to its network, especially in rural areas, while continuing to work with other partners to expand services to a wider base of CYSHCN than the agency has traditionally served. A focus will be on closing loops and evaluating services and referral patterns – and following up with families who did not qualify for ongoing services directly provided by CCSHCN, to ensure that they found and are accessing needed services.

National Performance Measure 6: (Data derived by averaging responses to 2 questions on CCSHCN clinic comment cards by youths or families of youths ages 13+, regarding work and independence, with a query of the CUP data system showing the percentage of CCSHCN patients 14-18 who

The % of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including health care, work, and independence

have plans for an adult health care provider)

- **This year's indicator: 61.7%**
- **Last year's indicator: 59.5%**

▪ **Last Year's Accomplishments:**

CCSHCN notes that state-generated transition scores have inched up, but improvement is still needed. Additionally, Kentucky's score (37.1%) on the 2009/2010 National Survey of Children with Special Health Care Needs represents a decrease from the 2005/2006 survey score (42.8%), and is now below the national average (40%). Through work on this NPM and SPM 8, CCSHCN has created a plan to increase agency capacity regarding transitions. Transition for CYSHCN as they move to adult services is an integral element of the discussion and planning that staff engage in with enrollees and their families. Outside of clinics, CCSHCN did outreach to previously unidentified CYSHCN to provide resources and support during this critical period through collaborations in activities such as Disability Mentoring Day and local and regional job fairs.

During the past year, the agency has been piloting a revised transition checklist in several sites. The updates are intended to simplify the checklist and increase active patient and family participation in the discussion. Rather than staff completing a computer-based checklist, the process now is guided by the interest areas of CYSHCN and families which are outlined on a paper form, as areas of focus are selected. Using this method, families are able to initiate the discussion, and the planning is more individualized and relevant to the CYSHCN's needs.

CCSHCN has been awarded a State Implementation/D70 Grant for its new "Kentucky Integrated Services for CYSHCN (KISC)" program, which is moving forward to seek out and develop community and state partnerships supporting the expansion of transition initiatives. Specific deliverables include educational workshops to empower youth to take control over their own medical condition, brochures and other materials to help youths become medically independent and self-sufficient through the transition process, and working with pediatricians to disseminate materials at developmentally appropriate times. Through grant activities, it is hoped that statewide, 2000 or more previously unidentified CYSHCN will receive services and resources necessary to make transitions to all aspects of adult life.

Involvement in the Kentucky Interagency Transition Council for Persons with Disabilities and the 11 Regional Interagency Transition Teams (RITT) across the state, which includes participating in transition information fairs, job/transition fairs & Disability Mentoring Day activities, assist CYSHCN to job shadow and explore employment. Being a part of these types of activities allows CCSHCN and F2F support parents to share information and encourage CYSHCN and their families to pursue work and independence as an adult.

The CCSHCN Transition Administrator serves as Chair of the Kentucky Statewide Council for Vocational Rehabilitation and on the Board of Directors for the Center for Accessible Living. Vocational Rehabilitation and Independent Living Centers are important links for transitioning youth to post-secondary education, work and independence. The Transition Administrator brings back first-hand information to CCSHCN staff and can serve as a liaison between CCSHCN and these agencies. The Transition Administrator attended both the spring and fall Council of State Administrators of Vocational Rehabilitation conferences where he gained knowledge of current initiatives and programs regarding vocational rehabilitation.

CCSHCN's age-specific transition surveys for youth were initiated during the previous year. Letters soliciting feedback on the surveys have been revised due to low response, and the survey will be opened up for input from a greater pool of CYSHCN, once technological adjustments are made. The goal is for CCSHCN to be able to gauge CYSHCN knowledge about various aspects of transitions, and use survey results to better provide such services for CYSHCN and their families.

The CSHCN Youth Advisory Committee (YAC) developed a tipsheet on requesting accommodations in school and improving self-advocacy skills. This document was distributed to CSHCN staff to share with CYSHCN and their families. In followup, the YAC suggested that CSHCN staff could develop some informational sheets for selected conditions, to help patients better understand their disabilities. CSHCN nurse administrators have developed several drafts, which are in the process of being reviewed by YAC. As a result of an article by YAC appearing in a statewide transitions newsletter, a representative of the group was asked to present at the Kentucky Department of Education's Career and Technical School Summer Awards Brunch about her transition from high school to college. The audience included approximately 35 high school teachers and college disability coordinators from across the state.

The CSHCN Parent Advisory Committee developed a tipsheet for parents on requesting accommodations in school, which supplements the YAC material designed for youth.

▪ **Current Activities:**

CSHCN has recently been designated by the Kentucky Board of Elections as a "disability service agency". As such, CSHCN is mandated to provide voter registration services pursuant to the National Voter Registration Act. The agency is in the process of implementing procedures wherein all 18 year-old CYSHCN enrolled in clinical programs will receive letters and voting forms upon application to the program, reapplication, and change of address. CSHCN staff will be available to assist them, and will transmit forms to the appropriate county clerk for processing. As part of the transitions discussion, staff are prompted to discuss in greater detail voter registration information as a means to help educate CYSHCN about their right to vote.

With the assistance of the YAC and PAC, CSHCN continues to improve the CSHCN Facebook page, so that it can be used to effectively distribute information about transitions issues. The Transition Administrator and other CSHCN staff submit topical or resource information regularly when an item of interest to CYSHCN is identified.

CSHCN and F2F continue to work with families on transition issues and to make the process easier for families to understand. Transition services are addressed through one-on-one discussions with families enrolled in CSHCN programs, by collaborating with community partners, and encouraging participation from all members of the disability community. As is indicated above, CSHCN has piloted a revised process in several areas and plans to roll out the new program statewide.

CSHCN staff continue to look for ways to address transition needs of unidentified CYSHCN in their respective communities and participate in events such as information fairs with local school districts and a variety of other agencies. Similarly, CSHCN continues to partner with transition liaisons from the state special education cooperatives.

The KISC program has assembled a steering committee and convened the first meeting of this committee to serve as the guiding force for the State Implementation/D70 grant. Several potential grant activities for the upcoming year including a 3 day weekend transition retreat for CYSHCN and their families, transition education workshops benefiting families and physicians, active participation in community transition fairs, a multi-agency parent collaborative, and an on-line Physician referral resource tool. All activities will increase community collaboration and sharing of resources used to assist transition age CYSHCN as they prepare and begin to transition into an adult health care model. Several community partners have expressed a desire to work in collaboration with CSHCN to reduce duplication of services and maximize the use of the resources available within the state. CSHCN staff worked together to develop a logic model that will serve as the road map to implementing the grant activities as well as a tracking tool to gauge the progress toward the grant objectives. KISC is actively developing the contract to continue support of the Bridges to the Future transition program operated by Kosair Children's Hospital. The collaboration with Kosair will be instrumental in helping CSHCN to meet the objectives of the KISC Grant by meeting the transition needs of CYSHCN and their families statewide.

▪ **Plan for the Coming Year:**

CCSHCN will be using the revised transition checklist, and continuing to work with YAC, PAC, families, schools and other community partners to identify and address transition needs of CYSHCN during the coming year. To increase agency capacity, CCSHCN continues to work to achieve the goals detailed in SPM 8. KISC will continue implementation through the planned activities listed above.

CCSHCN will be analyzing processes so that the agency identifies when patients most need transition services and who can best provide them. It is hoped that a focused approach with set criteria will meet the greatest needs of the most CYSHCN, and that the right people are getting the right services when they need them.

(Data derived by dividing the number of newborns receiving hearing screenings by the number of births during the year.)

▪ **This year's indicator: 98.1%**

▪ **Last year's indicator: 96.6%**

▪ **Last Year's Accomplishments:**

Collaboration began with the Kentucky Commission for Deaf and Hard of Hearing, which is providing a packet of information and resources for the EHDI program to send to all families of newborns diagnosed with permanent hearing loss. Similarly, collaboration began with the Hands and Voices "Guide by Your Side" program, which provides parent mentors to newly diagnosed families.

Purchases were made to replace aging audiometric equipment in all CCSHCN district offices and thereby increase access for families to appropriate diagnostic audiology services following "referral" from the newborn hearing screening.

The implementation of a statewide Cochlear Implant (CI) Program at CCSHCN has been an exciting development toward providing a team approach to support families and children who choose implantation as an access to communication/language. Bowling Green and Louisville CCSHCN offices provide CI activation and programming (MAPping) and approximately 20 children are enrolled in the CCSHCN CI program. All CCSHCN regional offices provide hearing aid related services in addition to initial CI candidacy evaluations. In light of the success of the CCSHCN CI program, plans have been made to expand CI MAPping services to Eastern Kentucky (CCSHCN Hazard).

Contact was made with the Public Health Departments and state certified Midwives to offer information regarding the screening and re-screening of newborns.

▪ **Current Activities:**

CCSHCN is actively working towards expansion of KY CHILD applications to allow for additional data to be transferred to CUP. A pilot program for direct electronic entry from hospital screening equipment to the KY CHILD hearing screen report is under discussion, although it is unlikely to be implemented in the coming year. Reduction of loss to follow up at diagnosis and early intervention is expected with increased access of electronic reporting.

Subsequent to participation in the National Initiatives for Children's Health Care Quality (NICHQ) Learning Collaborative, plan-do-study-act (PDSA) initiatives were implemented. As a result, an improvement in scheduling of audiology follow up appointments prior to newborn hospital discharge is noted. In addition, improved communication with specific physician practices regarding warranted follow up has been experienced statewide.

CCSHCN has expanded the collaborations with other partners, by providing a feasibility study for data exchange with First Steps, HANDS (KY Home Visiting Program) and Hands and Voices, to improve outcomes for children identified with hearing loss and to work with families to find resources and overcome barriers. Specifically, continued collaboration via Memorandum of Agreement with Part C (to address sharing of individual

**National
Performance
Measure 12:**

The % of newborns who have been screened for hearing before hospital discharge

identifiable information regarding enrollment in Early Intervention services) is resulting in an increase in the numbers of infants/toddlers referred for and receiving comprehensive audiology evaluations and related services at CSHCN offices throughout the state.

Collaborations and possible Memoranda of Understanding with surrounding states to facilitate the exchange of information begin in February 2012.

CCSHCN is also working with the birthing hospitals in increasing their compliance with data reporting requirements for newborn hearing screens. Bi-monthly emails are sent to hospitals that are out of compliance with timeframes for reporting so that the hospitals can engage staff in process improvement.

Funding requests for purchase of hearing aid programming equipment, diagnostic testing equipment and for expansion of the CI Program to the CSHCN Hazard, KY regional office have been submitted. Provision of requested equipment will enable staff audiologists to adhere to preferred practice patterns for the profession.

The letter disseminated by the EHDI program to parents of infants who refer or who present with risk factors has been revised (as a result of parent input) and its use will be implemented this year.

▪ **Plan for the Coming Year:**

Hospital scorecards are being piloted with relevant data and comparisons to state and national averages.

Evaluation and use of competency tools for Approved Audiology Providers who are non-audiologists will be piloted.

Annual site visits to all 52 birthing hospitals by CSHCN Audiology/Staff will be continued.

Improved documentation of enrollment in Early Intervention services (by age 6 months) for infants diagnosed with hearing loss by:

1. Partnering with Point of Entry consultants for Part C (including provision of Early Childhood Hearing Outreach (ECHO) training) by CSHCN Audiology staff; and
2. Pro-active collaboration between Family to Family Health Information Center (F2FHIC) parent consultants and EHDI/Audiology staff (using the CSHCN database task function to monitor)

State Performance Measure 7:

Decreased % of children, ages 0-18, receiving CSHCN services, with a Body Mass Index (BMI) at or above the 85th percentile

(Data derived from the CUP information system, by dividing the number of children enrolled in CSHCN clinics whose Body Mass Index (BMI) is at or above 85% by the total number of children enrolled in CSHCN clinics whose BMI has been measured.)

▪ **This year's indicator: 36.7%**

▪ **Last year's indicator: 35.2%**

▪ **Last Year's Accomplishments:**

Toward the goal of reducing the documented disparity between Kentucky CYSHCN and non-CYSHCN, CSHCN implemented its Healthy Weight Plan in May, 2011. The plan, aimed at reducing the proportion of CYSHCN who are at risk for being overweight or obese, and developed by a multidisciplinary and geographically diverse group of CSHCN staff from all levels of the organization, includes action in the areas of prevention, identification, and intervention/treatment.

The annual indicator on SPM 7 has inched up from 35.2% to 36.7%. This has not gone unnoticed; the Healthy Weight Committee is aware of the increase and feels that this year's indicator may be a reflection of a truer baseline than last year, as full implementation of BMI tracking did not occur during 2010 (as is reflected in the increasing denominator). During SFY 2011, 68% of respondents (over 1000 families) to comment on clinic survey cards indicated that CSHCN staff discussed healthy eating and nutrition with them.

2011 marked the rollout of CCSHCN's Healthy Weight initiative, including at its core, BMI tracking and individual health education, and the dissemination of health promotion materials to the CYSHCN population – a group who often find it more difficult to control weight and remain healthy. CCSHCN encourage healthy eating and physical activity, and reduced “screen time” through a 5-2-1-0 campaign. Many CCSHCN offices have employed an active scavenger hunt activity/game to reinforce the message; all offices/clinic environments are adorned with 5-2-1-0 posters and signs and stock trusted materials for patients, such as Chop-Chop magazine, articles from “Healthy & Fit”, “Healthy Favorites”, brochures from Jump Up and Go, and other media from sources like Bright Futures or “Let’s Move”.

Patients and CCSHCN physicians were provided with information on the new Healthy Weight initiative, and CCSHCN nurses were provided with talking points and “individualizable” letters to send with families of CYSHCN at or above the 85th percentile to their primary care physician or medical home – regarding treatment of obesity and obesity-related health problems.

A second dietitian was added in 2011 to CCSHCN's staff; dietitians housed in Lexington and Louisville are now available to attend clinics in the Eastern and Western halves of the state, respectively. Dietitians are available for consult at any time by any CCSHCN staff member. On a macro level, CCSHCN's dietitians attended several hearings of the Kentucky Legislature's Task Force on Childhood Obesity during the 2011 interim General Assembly session. These hearings were initiated by policy-makers to study strategies for addressing the problem of childhood obesity and to recommend strategies for addressing the problem. The hearings culminated in a report issued in December, 2011, recommending several strategies that encourage better nutrition and increased physical activity among children. Among the strategies highlighted during the hearings was the 5-2-1-0 approach, which has been implemented by CCSHCN and other organizations.

CCSHCN's Healthy Weight initiative maintains its materials on a page on the agency's intranet site, and periodically, messages or additional resources are shared with the public via the agency's Facebook social media site. Behind the scenes, CCSHCN administrative staff made the technology modifications to measure BMI-for-age percentiles necessary for reporting.

▪ **Current Activities:**

The focus of the Healthy Weight initiative has moved from the studying/reviewing/plan development phase to the implementation phase. As the plan is put into action by agency staff, committee members are monitoring with an eye toward refinement as necessary.

The State Performance Measure is well-known to staff, who continue to calculate BMI in clinic, plot BMI percentile on Centers for Disease Control (CDC) growth charts, and counsel families on the medical effects of childhood obesity when indicated. Some staff provide “prescriptions for physical activity”, and all refer to CCSHCN dietitians and/or health professionals or clinics trained in weight management. CCSHCN therapy staff engage patients individually in active physical activities per their needs, and the Healthy Weight Committee has considered the possibility of games or group activities (Dyna-band demonstrations, bean-bag tosses, exercise dice games, for example) to get patients active while waiting for their appointments. Unfortunately, staffing, time, and space issues prohibit structured activity with groups in clinic/clinic waiting room settings.

CCSHCN is committed to doing whatever it can to address overweight and obesity with CYSHCN and their families. Many barriers exist; lack of time during clinic appointments, family lack of readiness to make changes, or families not accepting that overweight/obesity is a legitimate concern; families who are more concerned with their children's special health care need(s) than they are about the risks of overweight or obesity. CCSHCN makes gentle efforts to overcome these barriers, and works with others to advance solutions to community concerns beyond the scope of the agency (for example, difficulty of finding or affording healthy food, or finding opportunities for

physical activity).

A key component of the Healthy Weight Plan concerns prevention. CCSHCN aims to participate in larger efforts to address the obesity epidemic. Given the tradition of interagency partnership at CCSHCN, and the recognition of the societal nature of problem and that no one agency can solve the problem, many CCSHCN regions are participating in regional/local councils supporting the Department for Public Health's CDC Obesity Prevention Grant. CCSHCN is also represented on the statewide Partnership for a Fit Kentucky.

▪ **Plan for the Coming Year:**

During the coming year, CCSHCN intends to assess staff comfort level with and buy-in to the initiative, and continue to develop staff capacity to address healthy weight issues. Planned activities include outreach by the Healthy Weight committee members to field supervisors and staff and follow-up on issues in statewide managers's meetings and through in-person and e-mail communications. Depending on the assessed need, CCSHCN's Healthy Weight Committee may create a continuing education opportunity or use an existing one. Staff physical activity/weight loss challenges to engage nurses on these issues are also a possibility.

Making dietitians available to CCSHCN clinics outside their home regions of Lexington and Louisville will be continued whenever possible. However, the practice of "tasking" the dietitians to make cold calls to at-risk patients has not met with a positive response. Alternate methods of intervention will be explored. Information system reports which identify patients with elevated BMIs who are coming to clinic in the next month will be sent out to the regional offices, and processes will be put in place so that CCSHCN staff know to counsel these patients and their families at clinic. Positive reinforcement strategies will be considered, for example, sending "congratulations" letters to patients who were at or above 85% of BMI and subsequently fall below 85% has been discussed, as has a quarterly award for the CCSHCN region who make the most outstanding efforts toward healthy weight counseling and education. The Healthy Weight committee will study data available regarding how rates of overweight/obesity vary across clinics and age groups, and may recommend targeted outreach as indicated. Inclusion of healthy weight intervention as a criteria in management audits of patient charts is an option which has been discussed. The committee will continue to meet regularly and evaluate the implementation of the plan and progress/lack of progress toward improved indicators on this SPM.

State Performance Measure 8:

Degree to which CCSHCN transition action plan is successfully completed and implemented

(Data derived by scoring the agency's progress/lack of progress toward implementing the agency's 13-point, 5-year Transition Action Plan – scoring on each item as follows: 0: activities have not yet begun; 1: activities have just begun; 2: activities are progressing; 3: activities are well-established; 4: activities are sustained)

[Below is a summary of the agency's Transition Action Plan, followed by a discussion:

1. Refine transition checklist for families and CYSHCN
2. Initiate tangible outreach to all CCSHCN clients upon 14th, 16th, and 18th birthdays, including surveys/assessments of current levels of independence and preparation for school/work
3. Cultivate awareness on available community resources through public resource guide, intranet social service page for staff, community education events
4. Develop & implement systems to measure impact of transition efforts & policies
5. Establish and distribute training documents in a variety of settings for providers regarding their roles in the transition process
6. Increase visibility and active involvement of CCSHCN Youth Advisory Committee
7. Revise agency procedures to conform to best practice consensus statement on health care transitions for CYSHCN
8. Initiate CCSHCN procedure encouraging children's signature on medical forms starting at age 12
9. Provide support to CYSHCN regarding accommodations available to enable management of health care issues in educational settings
10. Create a written health care transition plan by age 12 for CCSHCN children

11. Increase use of social media to reach and educate CYSHCN about pertinent health & transitions issues
12. Counsel & provide assistance with selection of adult health care providers, and encourage meetings with selected provider prior to discharge from CSHCN services.
13. Initiate transmittal of medical records (with release) to adult medical providers upon discharge.]

- **This year's indicator: 63.5%**
- **Last year's indicator: 46.2%**

▪ **Last Year's Accomplishments:**

During the past year, CSHCN's Transition Action Plan committee, oversaw continued implementation of the agency's 13-point, 5-year plan. The committee is chaired by the Transition Coordinator and includes members of both administrative management and field-level clinical services representatives. The committee met several times during the reporting period to share progress, as much of the work was achieved in subcommittees. This year's total score on the plan of 33 out of a possible 52 points marks a sizable improvement over the baseline total score last year of 25 out of a possible 52 points.

Update by plan number listed on detail sheets:

1. Activities are progressing. Much of CSHCN's work toward transitions centers around the transition checklist, a milestone-based guide that prompts care coordinators to address transition points with CYSHCN and their families. A subcommittee has revised and piloted a new checklist, designed to improve upon partnership with CYSHCN; full implementation is pending technology modifications.
2. Activities are sustained. Tangible outreach was implemented during the previous reporting period. Letters soliciting feedback on the surveys have been revised due to low response, and the survey will be opened up for input from a greater pool of CYSHCN, once technological adjustments are made. The goal is for CSHCN to be able to gauge CYSHCN knowledge about various aspects of transitions, and use survey results to better provide such services for CYSHCN and their families.
3. Activities are progressing. While some aspects of this goal have been completed (an intranet social service resource page for CSHCN staff, updates to the agency website and Facebook page regarding community education events), the public resource guide portion is currently on hold pending the outcome of goal number 1 with regard to the transition checklist update. A subcommittee has been formed to review care coordinator resource binders but is awaiting action on the transition checklist before taking action.
4. Activities are progressing. Transition surveys, clinic mini-surveys (comment cards), and revised transition checklists are used to measure the impact of transition efforts. Transition surveys and clinic mini-surveys are established. Again, the committee is awaiting full implementation of the transition checklist prior to generating more data to measure transition efforts.
5. Activities have just begun. The Kentucky Integrated Services for CYSHCN (State Implementation/D70) steering committee has begun discussion regarding possible plans in this area. Kosair Children's Hospital has started discussing with physicians and gaining commitment regarding their role in transitions services..
6. Activities are sustained. The Youth Advisory Council (YAC) role has steadily increased to the point where it has evolved into an effective and relevant advisory body. Activities during the past year include the creation of a topical tipsheet for distribution by CSHCN staff to CYSHCN, provision of helpful input on draft agency transition forms, and presenting on transitions at a gathering of educators.
7. Activities are progressing. The committee feels that each element and the entire transition plan represent the agency's effort towards revised procedures to conform to the best practice consensus statement.
8. Activities are well-established. An updated agency policy was issued during the

previous reporting year. Chart audits are conducted, using a tool incorporated in agency policy, to ensure that CYSHCN are signing their medical forms. Chart audits are a part of CCSHCN care coordinators' performance evaluation.

9. Activities are well-established. CCSHCN staff currently provides support to patients regarding accommodations available to enable management of healthcare issues in educational settings. The YAC and the Parent Advisory (PAC) have developed companion tipsheets (from youth and parent perspectives, respectively), which serve as resources for providing recommendations for advocating for one's needs to request accommodations in educational settings. CCSHCN care coordinators document in their service notes activities they provide to support parents in managing healthcare issues in the school system. Family consultants and F2F support parents provided one-to-one and professional support to approximately 200 families of CYSHCN during the reporting period regarding management of issues in the educational setting.
10. Activities are progressing. As mentioned above, the revised transition checklist has been revised and piloted, and will be going into production shortly. A "report card" is being considered for use in transition to adult health care. CCSHCN is looking at developing a care plan portion of the electronic health record, of which transitions would be a component.
11. Activities are progressing. CCSHCN's social media presence includes an agency Facebook page which previously was dormant. While the page is still growing in followers, there has been a significant increase in activity and posting during the reporting period. Going forward, a goal for the agency is to foster more two-way communication between the agency and the public.
12. Activities are progressing. CCSHCN staff currently counsels patients, provides assistance with the selection of adult health care providers, and encourages meetings with the selected providers prior to discharge. The KISC initiative is targeting development of a registry of adult health care providers that's are committed to serving CYSHCN transitioning from pediatric to adult care in a medical home-type environment.
13. Activities are sustained. CCSHCN currently initiates transmittal of medical records (with release) to adult medical providers upon discharge or identification, when the selected physician is known.

▪ **Current Activities:**

Revision of the agency's transition checklist represents an important achievement toward enhancing CCSHCN's ability to better serve the transition needs of CYSHCN. Full implementation of the revised transition checklist is occurring. As revisions are considered, the Transition Action Plan Committee continues to oversee the implementation of a variety of other transitions-related initiatives. Birthday letters, active involvement of the YAC and the transmittal of medical records to adult medical providers are established elements of CCSHCN practice; however, other plan elements are in various states of progress (see above) and continue to receive agency attention.

▪ **Plan for the Coming Year:**

Please see above; CCSHCN continues to address the elements of the five-year plan, focusing on those items which are progressing, followed by those elements on which work has not yet begun.