

Children's Special Health

Important Notes for Reviewers

- There are character limits on each of the sections which restrict the amount of material that may be written for a period of time. The section entitled “Last Year’s Accomplishments” allows for 4500 characters; “Current Activities” has space for 1500 characters; “Plan for the Coming Year” can contain no more than 3000 characters. The character counts include spaces used.
- Because of the severe limitation on the number of characters that may be used, several acronyms are used throughout the document. Please see below for a key to the acronyms used in this document.

APHL	Association of Public Health Laboratories
APS	EqualityCare Case Management contractor
CCHD	Critical Congenital Heart Defects
CCI	Common Client Index
CDPHE	Colorado Department of Public Health and Environment
CH	Children's Hospital
CHIPRA	Children’s Health Insurance Program Reauthorization Act
CPH	Community and Public Health
CSH	Children's Special Health Program
CSHCN	Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs
DD	Developmental Disability
DDD	Developmental Disabilities Division
DFS	Department of Family Services
DWS	Department of Workforce Services
EHDI	Early Hearing Detection and Intervention
EPICS	Department of Family Services computer system for dual eligibility
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
F2FHIC	Family 2 Family Health Information Center
GEIC	Governor's Early Intervention Council
GCDD	Governor's Council on Developmental Disabilities
IMD	Inherited Metabolic Diseases
IMM	Immunization Section
Kid Care CHIP	Wyoming's Children's Health Insurance Program
MFH	Maternal and Family Health Section
MHR	Maternal High Risk Program
MHSASD	Mental Health and Substance Abuse Division
MS	Master of Science
MSGRC	Mountain States Genetic Regional Collaborative
NBIC	Newborn Intensive Care Program
NBMS	Newborn Metabolic Screening
NNSGRC	National Newborn Screening and Genetics Resource Center
NS-CSHCN	National Survey-Children with Special Health Care Needs
OCIO	Office of the Chief Information Officer

OH	Oral Health
ORH	Office of Rural Health
PCP	Primary Care Provider
PDD	Pervasive Developmental Disorder
PHN	Public Health Nurse/Public Health Nursing
PIC/PEN	Parent Information Center/Parent Education Network
PLTI	Parent Leadership Training Institute
RFP	Request for Proposal
ROP	Retinopathy of Prematurity
SCID	Severe Combined Immunodeficiency
THR	Total Health Record
UPLIFT	An association that provides education and advocacy for parents, families, and the community, focusing on emotional, behavioral, and learning needs of children and youth
VSS	Vital Statistics Services
WDE	Wyoming Department of Education
WDH	Wyoming Department of Health
WIC	Women Infants and Children Program
WIND	Wyoming Institute for Disabilities
WOMH	Wyoming Office of Multicultural Health
WRIR	Wind River Indian Reservation
WyIR	Wyoming Immunization Registry

National Performance Measures

National Performance Measure 1: The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.

Last Year's Accomplishments (July 1, 2010 - June 30, 2011)

The objective for 2011 was 100%. In 2011, 100% of screen positive newborns received timely follow-up to determine a definitive diagnosis and clinical management for their conditions.

Wyoming NBMS continued to screen for 28 conditions. MFH contracted with CDPHE for testing, tracking, and staff training for newborn screening. The IMD Clinic at CH Denver, Colorado, provided consultation and education on metabolic conditions for Wyoming providers. Erica L. Wright, MS, Certified Genetic Counselor, Clinical Genetics and Metabolism, CH, served as a resource for questions regarding inherited metabolic diseases. In addition, hemoglobinopathy follow-up was provided by the University of Colorado School of Medicine.

CSH provided NBMS brochures to birth hospitals and providers.

Transportation and translation services were available for families who qualified for MFH and Medicaid programs to assist in obtaining additional screenings or to attend genetic/metabolic specialty clinics. In addition, MFH covered metabolic formula for children and youth who are eligible for the CSH program.

County Block grants continued to provide funding for PHN staff members to assist families who qualified for MFH services in obtaining needed care and referrals to appropriate community resources.

Wyoming continued sending out a "Submitter Report Card" to NBMS providers evaluating facilities on important specimen parameters, including submission time, specimen quality, and NBMS form completion. These reports, provided quarterly, improve the specimen submission process, accuracy of reports, and timeliness of follow-up.

In fall 2010, CSH participated in a quality improvement project aimed at decreasing the percentage of missing demographic information on the newborn metabolic screening cards by 10% at selected birthing facilities by December 2010. Of the two hospitals participating in the quality improvement project, Hospital A demonstrated a 17.4% reduction and Hospital B demonstrated a 66.6% reduction in missing demographic information. CSH will continue to monitor submitter report cards and help additional hospitals improve their performance as needed.

CSH participates with Colorado's NBMS Advisory Council. This group helps guide the NBMS process and assists MFH in defining timely follow-up for definitive diagnosis and clinical management. CSH staff continue to generate reports for primary care providers and birthing hospitals regarding babies with missed screens, and those that were screened less than 24 hours of age.

CSH personnel participate in the MSGRC which is designed to support the development and coordination of collaborative projects to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetics expertise and information in the context of a medical home. The MSGRC includes the states of Arizona, Colorado, Montana, New Mexico, Nevada, Texas, Utah and Wyoming. Active participation in MSGRC's meetings twice yearly has provided tremendous opportunities for learning and

collaboration. In June 2011, the CSH Program Manager was invited to become a member of the MSGRC Advisory Council.

CSH co-sponsors a booth with the EHDI program, annually, at the Wyoming Medical Society meeting.

Current Activities (July 1, 2011 – June 30, 2012)

The data system which links birth records and newborn metabolic lab results and helps ensure timely tracking and reporting was completed in December 2011.

April 2012, the newborn metabolic screening panel committee, specified by Wyoming Statute, convened and added SCID to the newborn panel; a date for implementation has not been set.

Close monitoring of specimen handling and transportation revealed a number of anomalies with the contracted courier service; the problems have been resolved. Saturday pick-ups from Wyoming's birthing facilities are being considered to shorten transportation times.

The contract for newborn testing with CDPHE has been extended through June 2014 (includes SCID testing). A contract has also been executed for metabolic follow up through December 2013; the contract for hemoglobinopathy follow up has been extended through June 2014. Contract negotiations with a Colorado provider are ongoing for SCID follow up.

The Rules and Regulations which govern NBMS are undergoing the regular rules promulgation process beginning May, 2012.

The Newborn Metabolic Screening Program Coordinator attended the APHL Conference November 2011. She will attend a Tandem Mass Spectrometry course at Duke University put on by the NNSGRC in May 2012.

Confirmatory testing is now paid for through the Newborn Metabolic Screening Program.

Plan for the Coming Year (July 1, 2012 – June 30, 2013)

The data system which links birth certificates and lab results has undergone an enhancement which will allow for better data collection regarding the number of Wyoming babies whose families declined screening. We will be analyzing the data, after collecting it for a year, to ascertain if there is a difference in the declination rate of screening in Wyoming as compared to opt-in and opt-out states' rates. Wyoming families must signify their choice to screen or not to screen by signing consent or decline forms which makes us unique in the United States.

Telemedicine efforts will continue as contracted follow up providers attempt to make long-term follow up more convenient for Wyoming families.

Careful examination of billing data which result in identification of data entry errors at CDPHE will continue in the coming year. Data entry errors are shared with the laboratory in an attempt to minimize them. Evaluation of errors over time may provide valuable insights into processes and may also guide future contract negotiations.

CSH will be redesigning the educational materials to reflect the addition of SCID to the screening panel.

Through established quality improvement practices, CSH will continue to contact providers to request that infant information on the newborn screening laboratory slips be completed in their entirety. This helps ensure quality record matches and improves timeliness for follow-up of missed screenings.

VSS and CSH will educate birth hospitals on how to correctly report acceptance or rejection of newborn screening by parents on birth certificates.

CSH will continue to work closely with Colorado's NBMS Advisory Council and with the MSGRC.

Continuous monitoring of courier services for the transportation of blood spot specimens will continue and problems will be resolved as identified.

CSH will continue to determine the viability of adding further conditions to the testing panel including, but not limited to, CCHD. CSH plans to update the Provider Toolkit and CSH website with additional conditions and algorithms. These updates will be sent to Wyoming providers who will submit either an initial or a second screen.

MFH will continue to cover metabolic formula for children and youth who are eligible for the CSH program.

CSH and EHDI will continue to coordinate and educate Wyoming providers and tertiary care facility staff about the importance of newborn hearing and metabolic screenings and referrals for patients.

County Block grants will continue to provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources.

CSH will, again, co-sponsor a booth with the EHDI program at the Wyoming Medical Society meeting.

National Performance Measure 2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

Last Year's Accomplishments (July 1, 2010 - June 30, 2011)

Data from the 2009-2010 National Survey of CSHCN show that 70.0% of Wyoming CYSHCN ages 0 to 18 years have families who partner in decision making at all levels and are satisfied with the services they receive. Data from previous survey years are not comparable to 2009-2010 for this performance measure. Wyoming has met its 2011 objective of 60.0%.

Collaboration with Medicaid and Kid Care CHIP focused on coordinating services for the MFH population and assisting families in navigating program coverage and eligibility requirements.

Medicaid continued translation reimbursement policy for eligible clients.

MFH travel benefits include travel assistance to all families eligible for MHR, NBIC, and CSH programs. Transportation and translation services for eligible MFH clients continued to be reimbursed at Medicaid rates. Identified barriers were addressed through a variety of partnerships to ensure adequate services continue.

County Block grants to PHN offices provided funding to local county offices. These funds allowed PHNs to work with CYSHCN families in order to maximize services.

MFH promoted well-child checks. CSH tracked and notified CSH clients' families of recommended periodic well-child checks via personal letter correspondence.

One of F2FHIC's primary functions is to assist families of CYSHCN in making informed choices about healthcare in order to promote good treatment decisions, cost effectiveness, and improved health outcomes. The F2FHIC is available as a resource for families of CYSHCN in Wyoming.

MFH has identified a curriculum that offers empowerment and civics skills to support parents and families in making desired changes for children. PLTI is an evidence-based curriculum with proven positive outcomes for children, families, and the community. This 20-week class is designed to bolster family involvement and leadership skills, while promoting the lifelong health, safety, and learning of children. Along with 68 hours of class time, PLTI participants each select and work on a community project addressing a need they identify in their community. This allows participants to put the skills they are learning on a weekly basis into practice and enhances the learning experience. Throughout PLTI, parents acquire a 'toolkit' of skills which support their efforts to improve systems of care at the family, community, and state levels. PLTI was successfully piloted in Laramie County in 2010 and 2011.

MFH enhanced education and promotion of MFH programs through conferences, webcasts, seminars, and trainings. MFH reviewed, revised, and updated brochures in early 2011. Some MFH brochures are targeted at providers and include a simple overview of all programs available, while others provide detailed program information for consumers and families. As new providers enroll in CSH, MFH sends brochures to be distributed to staff and patients at their clinics.

CSH funded a dietitian/nutritionist to complete the Jackson diabetes clinic team to work with patients and their families.

CSH funded a nutritionist to attend the First Step Diagnostic Clinic biannually. This funding ceased May 31, 2011 pending a comprehensive needs assessment regarding specialty clinics.

The CSH staff and a master's degree candidate intern developed a survey for providers to establish providers' needs for specialty clinics in May and June of 2011.

The CSH Program Manager was a member of the GEIC, which provides input to WDH and WDE on the Part C population (0 to 2 years). In addition, she served on the GCDD. Each council meets quarterly in various sites throughout the state. Parent advisory boards are invited to attend and provide input.

Current Year (July 1, 2011 – June 30, 2012)

MFH's long-standing tool called Packaging Wisdom was handed over to Wyoming's F2FHIC for updates/revisions. F2FHIC's "final" product is available through their website. Unfortunately, the final product was released to the public without MFH having the opportunity to review it. It included misinformation regarding CSH and was not the same product CSH had worked on with F2FHIC. Discussion has led to some changes.

The Specialty Clinic Survey was finalized in early 2012 and sent to healthcare professionals enrolled as CSH providers. A significant number of surveys have been received in response and analysis of the survey findings is underway to determine how specialty clinics services can be enhanced in the state.

The MFH Section Chief has been appointed to serve on the GEIC in place of the CSH Program Manager effective April 2012.

CSH are active members in planning and execution of the GCDD's MEGA conference that is held annually.

PLTI in Laramie County celebrated 28 graduates having acquired the skills to lead intentionally on behalf of Wyoming children. PLTI classes were piloted in Hot Springs County and on the WRIR. Community projects include, but are not limited to, support for families and their children with dyslexia, a children's playground built in a low-income trailer park, and expansion of a gross motor play area at a child development center. Roughly 25% of Wyoming PLTI participants report having a child with a "special need," though not necessarily a CSHCN.

Plan for the Coming Year (July 1, 2012 – June 30, 2013)

MFH will continue to promote well-child checks and develop educational materials. MFH will continue to distribute materials throughout Wyoming.

In an effort to integrate child healthcare records, MFH will continue to collaborate with WDH programs such as Medicaid and DDD. Recent efforts include the development of the THR and a data warehouse called the CCI. These efforts will help to reduce duplication of services.

The CSH Program Manager will continue to serve as a member of the GCDD. The Council will meet quarterly in various sites throughout the state, and parent advisory boards from the local child development centers will be invited to attend and give input.

Partnerships will continue with other WDH programs, which will focus on streamlining and coordinating services for the MFH population. These programs include Medicaid, Kid Care CHIP, IMM, DDD, Childcare Licensing, DFS, MHSASD, WIC, OH, WOMH, ORH, and PHN.

Transportation and translation services for MFH clients will continue to be reimbursed. Identified barriers will be addressed through a variety of partnerships, ensuring adequate services continue. MFH travel benefits will continue to include travel assistance to all families eligible for MHR, NBIC, and CSH programs. MFH travel

assistance is also available for families attending the biannual Cleft Palate Clinic held in Casper as well as Shriners hospitals.

MFH will continue to enhance education and promotion of MFH programs through conferences, webcasts, seminars, and trainings to assist families' abilities to be involved in decision making.

Partnership efforts with Family Voices at the regional and national level will be augmented through ongoing communication and guidance. This should help to encourage development of a Wyoming's Family Voices Chapter, which should, in turn, strengthen family involvement.

County Block grants to Wyoming counties will continue to provide funding for PHN to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources, encouraging their involvement with their child's care decisions.

MFH will continue to partner with the Wyoming F2FHIC as they support families of CYSHCN in Wyoming.

MFH will continue to support the expansion of PLTI through a second year pilot in both Hot Springs County and on the WRIR, including continued technical assistance for Laramie County PLTI. Each county must establish and maintain a local civic design team to work from the onset to guide the local initiative and secure funding to sustain PLTI. Campbell, Natrona, and Albany counties continue discussions around establishing PLTI pilot classes in their communities. Parents and families, including those with CYSHCN, who are equipped with a 'tool kit' of leadership skills through PLTI, are able to lead effectively at the family, community, and state level to ensure positive health and safety outcomes for all Wyoming children.

National Performance Measure 3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

Last Year's Accomplishments (July 1, 2010 - June 30, 2011)

Data from the 2009-2010 National Survey of CSHCN show that 44.6% of Wyoming CYSHCN ages 0 to 18 years receive coordinated, ongoing, comprehensive care within a medical home. This is less than the objective for Wyoming (50.0%), but does not represent a statistically significant decrease from the 2005-2006 percentage of 49.1%.

MFH emphasized the importance of obtaining a medical home for all children. This is especially important for CYSHCN whose conditions may be complex and requires more of the provider's time but who benefit most from a central point of care coordination.

Clients eligible for MFH who may also be eligible for Medicaid or Kid Care CHIP, but who did not access services or follow through with treatment plans, were referred to PHN and APS for intervention.

Cooperation among MFH, PHN, and APS for complex cases ensured that clients received needed services. Efforts continued to be directed towards coordinating care between pediatric specialists and the PCP by obtaining medical records and assuring that a copy is available for the PCP and PHN staff. PHN worked with the PCP in case management and assisted with care coordination.

MFH emphasized early screening and treatment to increase the child's ability to reach optimum health through promoting EPSDT. A part of the promotion of well-child checks is to educate the families about what to expect from a medical home. Some CYSHCN do not receive regular well-child checks due to the number of specialty visits that are required.

County Block grants to PHN offices continued allowing PHNs to be an entry point for CSH programs.

To assist PCPs in identifying resources available for their CYSHCN patients, MFH staff updated a pediatric specialty clinic directory and distributed it to PHN and Wyoming providers. In March 2011, a final paper distribution of the specialty clinic directory was mailed. From quarter one 2011 forward, the specialty clinic directory will be updated continuously and posted exclusively on the CSH website. This will reduce postage costs and should provide interested parties with the most up to date information available.

MFH expanded travel benefits include travel assistance to all families eligible for MHR, NBIC, and CSH programs.

MFH has access to the electronic medical records of MFH clients who are seen at CH, in Colorado. This has greatly enhanced MFH's ability to provide effective care coordination and to assist the PHN staff and providers as they support MFH clients.

Wyoming is in the implementation phase of the THR. The first of four releases have been approved and the THR is up and running in one provider office. Providers will be added one at a time with five providers in line to implement the THR. The connections for EPSDT will be built in and customized through the CHIPRA grant sometime in the next year. Once completed, the THR will support the medical home model and provide tracking for EPSDT.

CSH partners with OH in Cleft Palate clinics that are held twice per year in Casper, Wyoming, by providing staffing support. The services received by patients are free of charge.

Current Activities (July 1, 2011 - June 30, 2012)

WDH is working to increase the number of Wyoming children who have a medical home, but the process is challenging. Pediatricians are unevenly distributed throughout the state and family practice physicians have high caseloads. Families are encouraged to have one PCP with PHNs and other community resources helping to carry out some of the functions of a medical home.

CSH is exploring a pilot opportunity, with MSGRC funding, to provide parent partners in PCP offices who would assist families of CYSHCN in linking up with community resources and dealing with unique education and transition issues.

Continuous updates to the specialty clinic directory continue; the directory is available on the CSH website.

MFH continues to assist in coordinating care between pediatric specialists, the PCP, and PHN.

The THR is now operational and currently is being used in 15 practices and 5 PHN offices. That involves 34 providers and 140 users (including doctors, nurses, schedulers, etc.). There are approximately 31,000 patients whose records are in the THR.

CSH supported OH's Cleft Palate clinics by providing clinic staffing in October 2011 and April 2012.

CSH supported the Wyoming Telehealth Consortium, which is lead by the Department of Health and the OCIO financially by providing funding for 111 cameras and 100 licenses. PHN offices and private practices will be able to connect to specialists at a distance for individual patient consultations.

Plan for the Coming Year (July 1, 2012 - June 30, 2013)

MFH will continue current activities and work to enhance the partnership with the F2FHIC in an effort to promote the importance of establishing a medical home.

CSH will continue to explore opportunities to partner with MSGRC in development of a parent partner program for PCPs offices in Wyoming.

Coordination will continue as needed among MFH, PHN, and APS. This type of coordination is especially important for children hospitalized out-of-state and in need of care coordination as they return to the local community. MFH emphasizes the importance of well-child checks in addition to specialty care visits. Clients will be encouraged to visit their PCP and specialist on a regular basis.

MFH will continue to emphasize early screening and treatment to increase each child's ability to reach optimum health through promoting EPSDT and educating families and providers on the benefits of a medical home.

MFH will collaborate with other partners and direct efforts towards furthering the medical home initiative in Wyoming.

County Block grants to Wyoming counties will continue to provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources.

MFH will continue to partner with the University of Utah and Wyoming 2-1-1 in establishing a Wyoming presence on the Medical Home Portal (<http://www.medicalhomeportal.org>)

CSH will continue to support OH's Cleft Palate clinics by providing in-kind staffing twice per year. Each clinic session lasts two days.

IMM records from the WyIR have been integrated into the THR and more WDH databases are planned for connections.

National Performance Measure 4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Last Year's Accomplishments (July 1, 2010 – June 30, 2011)

Data from the 2009-2010 National Survey of CSHCN show that 58.0% of the families of Wyoming CYSHCN ages 0 to 18 years have adequate private and/or public insurance to pay for the services they need. This is less than the objective for 2011 (65%), but does not represent a statistically significant decrease from the 2005-2006 percentage of 59.9%.

Medicaid and Kid Care CHIP utilized the same application, streamlining the eligibility process. Families were required to apply for Medicaid and Kid Care CHIP prior to becoming eligible for MFH services. This policy allows families to have more comprehensive healthcare coverage. Qualified non-citizens continued to be eligible for services, while illegal non-citizens were ineligible. In a reciprocal agreement, families applying for Medicaid and Kid Care CHIP who have a CYSHCN were referred to MFH to determine eligibility for MFH services. Referrals continued to be shared among APS, Kid Care CHIP, DFS, and MFH.

MFH provided coverage for services Kid Care CHIP did not cover, such as hearing aids, therapy vests, orthognathic surgery, translation services, genetic testing, travel assistance, and additional vision follow-up appointments.

MFH provided follow-up of dual-eligible clients through the EPICS data system utilized by DFS. Local services and program benefit information were examined for each client.

For complex cases, a plan of treatment was agreed upon among MFH, PHN, and APS. These cases have included children hospitalized out-of-state in need of care coordination to return to their local community. Treatment plans usually included recommending clients visit their PCP or specialist on a regular basis.

MFH and PHN staff contacted CSH families needing to reapply for Medicaid or Kid Care CHIP, assuring healthcare coverage continued.

As a best practice strategy, MFH advocated that Wyoming families maintain a rapport with pediatric specialists and sub-specialists to ensure continuity of care. This included services obtained out-of-state.

The Wyoming Genetic Counseling Services Program, allowed individuals, who have inadequate insurance, or no insurance, to obtain consultation services at no cost.

County Block grants to Wyoming counties provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources.

Because there are no tertiary care facilities within Wyoming, MFH, PHN, Medicaid, EHDI and Part C staff members continued to coordinate visits to hospitals in surrounding states to educate tertiary care facility staff regarding services available in Wyoming when families return home. Annual tertiary care facility visits included meeting with hospital staff members and reviewing Wyoming programs that support Wyoming families. This helped to ensure Wyoming families are referred to WDH programs.

CSH partners with OH in Cleft Palate clinics that are held twice per year in Casper, Wyoming, by providing staffing support. The services received by patients are free of charge.

Current Activities (July 1, 2011 - June 30, 2012)

Referrals continue to be shared among APS, Medicaid and Kid Care CHIP, DFS, and MFH. MFH also collaborates with Kid Care CHIP to provide gap-filling services to dual-eligible clients.

MFH and PHN continue to follow-up with CSH families who need to reapply for Medicaid or Kid Care CHIP, assuring healthcare coverage is continued.

MFH provides services, such as care coordination and appointment reminders, that Medicaid or Kid Care CHIP do not provide.

Medicaid and Kid Care CHIP utilize the same application, streamlining the eligibility process. Families are now able to apply for Kid Care CHIP online at <http://healthlink.wyo.gov>.

As a result of the RFP process, Wyoming Genetic Counseling Services are now being provided by the University of Utah. Beginning January 1, 2012, under new contract terms, the providers will no longer bill insurance companies or Medicaid for consultations. Families continue to receive consultations at no out of pocket cost.

CSH supported OH's Cleft Palate clinics by providing clinic staffing in October 2011 and April 2012.

Plan for the Coming Year (July 1, 2012 – June 30, 2013)

Referrals will continue to be shared among APS, Kid Care CHIP, DFS, and MFH.

MFH will collaborate with Medicaid and KidCare CHIP to provide gap-filling services to dual-eligible clients.

MFH will continue to access EPICS to enhance service coordination to determine local services and program benefit information. Information will be shared among collaborating agencies, and MFH and PHN will continue follow-up with families to reapply for WDH programs and other associated entities to ensure healthcare coverage continues.

Coordination will continue among MFH, PHN, and APS for complex cases, and MFH will continue to recommend clients visit their PCP or specialist on a regular basis.

MFH will continue to participate with Kid Care CHIP in networking with communities throughout the state. This will allow Wyoming citizens to be informed about MFH, Kid Care CHIP and Medicaid programs.

MFH will continue to advocate for travel reimbursement for out-of-state pediatric specialist appointments for dual-eligible clients. This helps families maintain the rapport they have built with specialists and encourages compliance with the treatment plan.

Medicaid and Kid Care CHIP will continue to utilize the same application, streamlining the eligibility process. Families are able to apply for Kid Care CHIP online at <http://healthlink.wyo.gov>.

Wyoming Genetic Counseling Services will continue to allow individuals, regardless of insurance status, to be seen for consultation at no cost.

County Block grants to Wyoming counties will continue to provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources.

MFH, PHN, Medicaid, EHDI, and Part C staff will continue to coordinate visits to educate tertiary care facilities to ensure Wyoming families are referred to WDH programs.

CSH will continue to support OH's Cleft Palate clinics by providing in-kind staffing twice per year. Each clinic session lasts two days.

National Performance Measure 5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Last Year's Accomplishments (July 1, 2010 – June 30, 2011)

Data from the 2009-2010 National Survey of CSHCN show 63.9% of the families of Wyoming CYSHCN ages 0 to 18 years report that community-based service systems are organized so they can use them easily. This is less than the objective for 2011 of 90.0%. This percentage is not comparable to data from previous survey years.

MFH updated a specialty clinic directory and distributed it to PHN and Wyoming providers to provide awareness to PCPs and families needing these services.

MFH contracted with CDPHE for testing, tracking, and staff training for newborn metabolic screening. The IMD Clinic at CH Colorado provided consultation and education on metabolic conditions for Wyoming providers and families. The University of Colorado School of Medicine is contracted to provide follow up for children identified on newborn screening as having a hemoglobinopathy. MFH continued to enhance education and promotion of newborn screening through conferences, webcasts, seminars, and trainings for staff and other associated entities.

Families applying for Medicaid and Kid Care CHIP who have a CYSHCN were referred to MFH to determine eligibility for MFH services. Referrals continued to be shared among APS, Kid Care CHIP, DFS, PHN, and MFH.

For complex cases, a plan of treatment was agreed upon among MFH, PHN, and APS. Treatment plans include recommending clients visit their PCP or specialist regularly.

MFH, PHN, Medicaid, EHDI, and Part C continued to coordinate and educate tertiary care facilities in surrounding states about programs available to Wyoming families. This ensures families are referred to WDH programs upon discharge from the hospital.

County Block grants to Wyoming counties continued to provide funding for PHN to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources.

Numerous pediatric specialty clinics are conducted state-wide to assist families and reduce travel time and expense. However, suspension of the CSH program financial assistance for specialty clinics took place on May 31, 2011 as a result of an audit of historical practices. CSH and a master's degree candidate intern developed a survey for providers to establish providers' needs for specialty clinics in May and June of 2011.

MFH expanded travel benefits to include travel assistance to all families eligible for MHR, NBIC, and CSH programs.

Diagnosis information sheets were distributed to parents of children who are affected by the following conditions: Autism/PDD, Cerebral Palsy, Clotting Disorders, Convulsive Disorders, Cystic Fibrosis, Developmental Delay, Type 1 Diabetes Mellitus, Esotropia/Exotropia, Juvenile Idiopathic Arthritis, Neurofibromatosis, Osteogenesis Imperfecta, ROP, and/or Tympanostomy Tubes as an insert with the initial CSH eligibility letter and annually at renewal.

MFH updated brochures in early 2011. Some MFH brochures are targeted at providers and include a simple overview of all programs available, while others provide detailed program information for consumers. As new providers enroll, MFH sends brochures to be distributed to staff members and patients at their clinics.

MFH held a strategic planning meeting of stakeholders to address the new MFH State Priority to build and strengthen services for successful transitions for children and youth with special health care needs and work on an issue brief regarding this topic began.

MFH has identified a curriculum that offers empowerment and civics skills to support parents and families in making desired changes for children. PLTI is an evidence-based curriculum with proven positive outcomes for children, families, and the community. This 20-week class is designed to bolster family involvement and leadership skills, while promoting the lifelong health, safety, and learning of children. Along with 68 hours of class time, PLTI participants each select and work on a community project addressing a need they identify in their community. This allows participants to put the skills they are learning on a weekly basis into practice and enhances the learning experience. Throughout PLTI, parents acquire a 'toolkit' of skills which support their efforts to improve systems of care at both the community and state level.

CSH partners with OH in Cleft Palate clinics that are held twice per year in Casper, Wyoming, by providing staffing support. The services received by patients are free of charge.

Current Activities (July 1, 2011 – June 30, 2012)

MFH's long-standing tool called Packaging Wisdom was handed over to Wyoming's F2FHIC for updates/revisions. F2FHIC's "final" product is available through their website at http://www.wpic.org/WYF2FHIC/PDF/PackagingWisdom/PackagingWisdom_0112.pdf. Unfortunately, the final product was released to the public without MFH having the opportunity to review it. It included misinformation regarding CSH and was not the same product CSH had worked on with F2FHIC. Discussion has led to some changes.

Work on the issue brief addressing the MFH State Priority to build and strengthen services for successful transition for children and youth with special health care needs is still in progress.

The Specialty Clinic Survey was finalized in early 2012 and sent to PCPs. A significant number of surveys have been received in response and analysis of the survey findings is underway to determine how specialty clinics services can be enhanced in the state.

PLTI in Laramie County celebrated 28 graduates having acquired the skills to lead intentionally on behalf of Wyoming children. PLTI classes were piloted in Hot Springs County and on the WRIR.

CSH supported OH's Cleft Palate clinics by providing clinic staffing in October 2011 and April 2012.

CSH is exploring a pilot opportunity, with MSGRC funding, to provide parent partners in PCP offices who would assist families of CYSHCN in linking up with community resources and dealing with unique education and transition issues.

Plan for the Coming Year (July 1, 2012 – June 30, 2013)

CSH will continue support of the Wyoming Telehealth Consortium, lead by the Department of Health and the OCIO, following financial support in summer 2012 which provided funding for 111 cameras and 100 licenses, enabling PHN offices and private practices to connect to specialists at a distance for individual patient consultations.

Diagnosis information sheets continue to be distributed to parents of children who are affected by various conditions with both the initial eligibility letters and at renewal.

Work with the F2FHIC will continue regarding Packaging Wisdom. In addition, MFH will continue current activities and work to enhance the partnership with the F2FHIC in their efforts to ensure that the community-based service systems are organized so that families of CYSHCN can use them easily.

Work on the issue brief addressing the MFH State Priority to build and strengthen services for successful transition for children and youth with special health care needs will be completed and disseminated.

Transportation and translation services will continue to be available for families who qualify for MFH programs.

Efforts will continue to be directed towards coordinating care between pediatric specialists, sub-specialists, and the PCP by requesting copies of medical records and assuring that a copy is available for the PCP and PHN staff.

MFH will continue to participate with Kid Care CHIP in networking with communities throughout the state. This allows Wyoming citizens to be informed about MFH, Medicaid and Kid Care CHIP programs. Families applying for Medicaid and Kid Care CHIP who have a CYSHCN will continue to be offered a referral to MFH programs.

MFH, PHN, Medicaid, EHDI, and Part C will continue to coordinate and educate tertiary care facilities to ensure Wyoming families are referred to WDH programs.

County Block grants to Wyoming counties will continue to provide funding for PHN to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources.

The CSH website will be updated to include additional information on transitions for families who have a child with special health care needs.

MFH and PHN staff contact CSH families to reapply for WDH programs and other associated entities, assuring healthcare coverage is continued.

MFH will support a second year pilot of PLTI in both Hot Springs County and on the WRIR

CSH will continue to support OH's Cleft Palate clinics by providing in-kind staffing twice per year. Each clinic session lasts two days.

MFH will collaborate with other partners and direct efforts towards furthering the medical home initiative in Wyoming including the MSGRC parent partner program.

National Performance Measure 6: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Last Year's Accomplishments (July 1, 2010 – June 30, 2011)

Data from the 2009-2010 National Survey of CSHCN show that 47.4% of youth with special health care needs received the services necessary to make transitions to all aspects of adult life, including adult healthcare, work, and independence. This is similar to the percent reported last year (47.0%).

MFH collaborated with the GCDD and Vocational Rehabilitation to assure efforts were made for CYSHCN transitioning to all aspects of adult life. The CSH Program manager serves on the Employment subcommittee for the GCDD.

As a resource, MFH provided families and clients who are transitioning from youth to adult services with a document listing available resources and suggested topics that need to be addressed prior to transition. In addition, MFH provided a tool for families to use for transitioning called Packaging Wisdom. Packaging Wisdom is available on the WDH website. It was offered through some PHN offices.

Transportation and translation services for eligible MFH clients continued to be provided.

County Block grants to counties continued to provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referrals to appropriate community resources including available transition services.

Through the needs assessment process, MFH chose to build and strengthen services for successful transitions for children and youth with special health care needs as a priority for the next five years.

MFH held a strategic planning meeting of stakeholders to address the new MFH State Priority to build and strengthen services for successful transitions for CYSHCN.

Current Activities (July 1, 2011– June 30, 2012)

MFH continues to collaborate with the GCDD, Wyoming Protection and Advocacy System, Inc., and Vocational Rehabilitation to assure efforts are being made for CYSHCN transitioning to all aspects of adult life.

MFH continues to provide families and clients who are transitioning from youth to adult services with a document listing available resources and suggested topics that need to be addressed prior to transition. We are including the DWS Transition brochure with these mailings.

County Block grants to Wyoming counties continue to provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referring them to appropriate community resources, including available transition services.

The CSH Program Manager worked with the WIND on the Think College initiative to identify opportunities for young people with DD to attend college.

CSH supported the Wyoming Telehealth Consortium, lead by the Department of Health and the OCIO, financially by providing funding for 111 cameras and 100 licenses. PHN offices and private practices will be able to connect to specialists at a distance for individual patient consultations. These telehealth connections will also allow for transition appointments with specialists and young adult and adult PCPs.

MFH enhanced the tools provided for families to use for transitioning including updating and enhancing our webpage information.

Plan for the Coming Year (July 1, 2012 – June 30, 2013)

MFH will continue current activities and work to enhance the partnership with the F2FHIC in their efforts to ensure CYSHCN receive the services necessary to make transitions to all aspects of adult life, including adult healthcare, work, and independence.

MFH will hold additional strategic planning sessions with partners and stakeholders around transition to ensure that CYSHCN have the supports necessary for successful transitions in all aspects of their lives.

MFH will strengthen collaborative relationships with other advocacy agencies providing services to the MCH population in Wyoming including PIC/PEN and UPLIFT.

MFH will endeavor to strengthen Family Voices locally through collaboration at the national level.

MFH will continue to attend, participate, and fund conferences provided for the MFH population. MFH staff will staff booths at these conferences to ensure information is disseminated about MFH programs.

MFH will continue County Block grants to Wyoming counties to provide funding for PHN staff to assist families who qualify for MFH services in obtaining needed care and referring them to appropriate community resources including available transition services.

MFH will continue to enhance the tools provided for families to use for transitioning including updating and enhancing our webpage information

The CSH Program Manager will continue to work with WIND on the Think College initiative to identify opportunities for young people with DD to attend college.

CSH will continue to support the Wyoming Telehealth Consortium and will encourage the use of telehealth appointments to help bridge the gaps between young adult and adult healthcare.

In partnership with MSGRC, a Parent Partner Pilot Program, scheduled to begin in January 2013, will help parents and youth with issues of transitioning from pediatric care to adult care and identification of community resources.

State Performance Measures

State Performance Measure 9: The capacity to collect, analyze, and report on data for children and youth with special health care needs.

Last Year's Accomplishments (July 1, 2010 – June 30, 2011)

State Performance Measure 9 is a process measure that tracks progress in five areas including identifying data sources for CYSHCN and analyzing existing data, creating a comprehensive report on CYSHCN, identifying data gaps, assessing capacity to address data gaps, and creating a plan to address data gaps. Each area is scored, and the scores are totaled. In 2011, the overall score increased to 1 from 0 in 2010.

In 2011, the CPH Epidemiology Section and MFH collaborated on a priority overview document which provides a comprehensive summary of Building and Strengthening Data Capacity for Children and Youth with Special Health Care Needs. The priority overview is available at <http://www.health.wyo.gov/familyhealth/mchept/index.html>.

A data system linking newborn metabolic screening results, as processed by the Colorado Department of Public Health Laboratory, to birth records was completed. This system assists in ensuring timely follow-up for children identified as having metabolic disorders and identifies infants who did not receive a newborn metabolic screen.

Current Activities (July 1, 2011– June 30, 2012)

The CSH data system was expanded to allow PHNs statewide to enter applications and supporting documentation for the CSH program in real time. The system was launched in April 2012.

The CSH program began conducting a needs assessment related to specialty clinics in Wyoming which will help determine the need for specific specialty clinics and may drive choices for appropriate locations for the clinics to be held. In April 2012, surveys were sent to all Wyoming providers who treat pediatric patients. Providers are asked about their referral practices with regard to Wyoming specialty clinics and their opinions on the specialties offered.

MFH collaborated with Epidemiology to apply for the Graduate Student Intern Program. The proposed project is to create a comprehensive report on Wyoming CYSHCN to address one of the five goals being used to measure progress in addressing this priority. Wyoming was selected to have an intern and was matched with a student in April 2012. Beginning in June 2012, the intern will create a report on CYSHCN in Wyoming using data from the NS-CSHCN based on an example from North Dakota. The majority of the data will be obtained from the Data Resource Center for Child and Adolescent Health (www.childhealthdata.org). Additional analyses of the NS-CSHCN data set will be conducted locally using SAS and SUDAAN. The final product will be a report on Wyoming's CYSHCN.

Plan for the Coming Year (July 1, 2012 – June 30, 2013)

The expanded CSH data system, which was launched in April 2012, allows PHNs to submit program applications. Client information is available real-time for viewing which allows PHNs to utilize the system to better coordinate care for CSH clients.

The Genetic Clinic services contract was awarded to the University of Utah for calendar year 2012. Data required from the Contractor after each clinic date for each patient includes: if they attended their scheduled

appointment, diagnosis/diagnoses, when follow-up is needed, and the tests that were ordered/obtained. Also, semi-annually, the Contractor will submit a written report which will detail patient demographics, race/ethnicity, and primary care providers.

As a result of the specialty clinic needs assessment, the CSH program will make programmatic decisions concerning future specialty clinics.

Data on CYSHCN will continue to be utilized from the NS-CSHCN and the WDH CSH data system.

The CSH Program will partner with F2FHIC to conduct a survey of parents of CYSHCN.

MFH will assemble an advisory committee to review the CYSHCN report and identify data gaps.