

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Health Resources and Services Administration**

Maternal and Child Health
Genetic Services Branch
Division of Services for Children with Special Health Needs

***Regional Genetic and Newborn Screening Services Collaboratives:
Heritable Disorders Program***

Announcement Type: Competing Continuation
Announcement Number: HRSA-12-138

Catalog of Federal Domestic Assistance (CFDA) No. 93.110

FUNDING OPPORTUNITY ANNOUNCEMENT

Fiscal Year 2012

Application Due Date: January 27, 2012

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Deadline extensions are not granted for lack of registration.
Registration may take up to one month to complete.*

**Release Date: December 16, 2011
Issuance Date: December 19, 2011**

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Authority: Section 1109 of the Public Health Service Act, as amended (42 U.S.C. § 300b-8).

Executive Summary

The purpose of this funding opportunity announcement is to solicit applications for the Regional Genetic and Newborn Screening Services Collaboratives: Heritable Disorders Program. The Collaboratives will provide a regional infrastructure of public health genomics expertise to improve, expand, strengthen, and evaluate access to a system of genetic services and the quality of those services to improve health outcomes for children, youth and adults across their life course.

Funds available: Approximately \$4,200,000 is expected to be available annually to fund seven (7) grantees. Applicants may apply for a ceiling amount of up to \$600,000 per year. The award amount is dependent on the activities reflected within the project narrative and budget. The grant will be funded for five (5) years, subject to the availability of funding for years 2–5 and satisfactory grantee performance. Eligible applicants include: (1) a state or a political subdivision of a state; (2) a consortium of two or more states or political subdivisions of states; (3) a territory; (4) a health facility or program operated by or pursuant to a contract with or grant from the Indian Health Service; or (5) any other entity with appropriate expertise in newborn screening, as determined by the Secretary.

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I. Funding Opportunity Description

1. Purpose

This announcement solicits applications for the Regional Genetic and Newborn Screening Services Collaboratives: Heritable Disorders Program. The Genetic Services Branch (GSB) within the Division of Services for Children with Special Health Needs (DSCSHN) of the Maternal and Child Health Bureau (MCHB) is the lead for funding this grant project. The Grant Program includes: seven (7) Regional Genetic and Newborn Screening Services Collaboratives (RC) [HRSA-12-138] and one (1) National Coordinating Center (NCC) [HRSA-12-139].

Each RC will serve effectively as a regional center to: expand and improve newborn screening and genetic services for individuals affected or at risk for heritable disorders and their families; translate genomic medicine into health care delivery systems; and assist states in strengthening their capacity to provide genomic information and services to the public. The RC will continue to undertake a regional approach to address the maldistribution of genetic resources, with focus on reducing disparities among different socioeconomic, racial, ethnic and rural groups. Strategies to address underserved populations include collaboration with other HRSA initiatives, such as MCHB Title V services and other MCHB programs for the hemoglobinopathies, hemophilia and autism, as well as community-based services, medical home implementation, transition for youth and young adults, and health insurance and financing.

Proposed regional projects are expected to:

- Connect families and health care providers;
- Develop private-public partnerships;
- Facilitate provider education and training;
- Create and disseminate just-in-time resources and evidence-based clinical guidelines;
- Increase access to patient resources and materials through web and social media technologies;
- Enable data system integration and transparency;
- Utilize integrated tools, such as, health record technology, telemedicine and other distance communication;
- Address financial barriers/issues and incentives to families and providers;
- Address concerns and solutions to genetics privacy and equity;
- Quantitatively and qualitatively evaluate regional projects using established national outcome measures; and
- Develop quality improvement activities to improve patient outcomes and services efficiency.
- Promote and disseminate projects of regional, interregional and national significance.

Although the infrastructure of the RC may be multi-centered, multi-state, or virtual, it must be headquartered within its proposed region. Regional activities are built upon the collaboration of state and local public health agencies and community organizations, genetics subspecialists and other subspecialists, primary care providers, professional organizations, and individuals affected with genetic conditions and their families. All states and US territories are included in a RC as designated by HRSA for nationwide coverage. The Regional Collaboratives interact with and are supported by a NCC that serves as the primary vehicle for information sharing among the RCs; and works to develop, implement, disseminate, and evaluate projects of national significance.

To address both state and regional capacity, the applicant will serve one (1) of the seven (7) regions identified below.

- Region 1. New England States - CT, MA, ME, NH, RI, VT.
- Region 2. New York-Mid-Atlantic States - DC, DE, MD, NY, NJ, PA, VA, WV.
- Region 3. Southeast States - AL, FL, GA, LA, MS, NC, PR, SC, TN, VI.
- Region 4. Midwest States - IL, IN, KY, MI, MN, OH, WI.
- Region 5. Heartland States - AR, IA, KS, MO, ND, NE, OK, SD.
- Region 6. Mountain States - AZ, CO, MT, NM, NV, TX, UT, WY
- Region 7. Western States - AK, CA, HI, ID, OR, WA, Guam.

PROGRAM GOALS

The **Program Goal** of the RC is to provide regional leadership to improve, expand, strengthen, and evaluate access to a system of genetic services and the quality of those services to improve health outcomes for children, youth and adults across their life course. Specifically, the **Goals** are:

- 1) Continue to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and other subspecialty expertise.
 - a. Move individuals with genetic conditions and their families to the forefront of decision-making in the development of systems of services and demonstrate their satisfaction with the quality of the services throughout the life course.
 - b. Address gaps and barriers to genetic services, especially for the medically underserved, populations in rural areas, and individuals and families uninsured.
- 2) Apply the translation of genome-based knowledge, genomics best practices, and new technologies to education and training, services, and dissemination to improve population health.
 - a. Incorporate evidence-based clinical guidelines and genetic medicine practice models, using Health Information Technology (HIT) including but not limited to electronic health records, personal health records, telehealth, distance learning technology, and web portals.
 - b. Disseminate and promote project information and outcomes through various media; examples are publications, social media, and public health information campaigns.
- 3) Quantitatively and qualitatively evaluate through program evaluation outcomes of projects undertaken to accomplish their goals.
 - a. Facilitate integrated data collection and assessment systems using national quality indicators (ex. Healthy People 2020) and data for project evaluation.
 - b. Collect data for national quality indicators to ensure that all children and adults have a chance for best possible outcomes.
 - c. Continue quality improvement projects and Learning Collaboratives conducted in the Medical home and specialty clinics to improve the quality of health care.
 - d. Continue the use of genetic systems assessment tools.

The applicant must identify, at a **MINIMUM, two (2) PROGRAM PRIORITIES** (listed below) to address the **PROGRAM GOALS** and to sustain for the **FIVE (5) year grant cycle**.

- 1) Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care.

- a. Strive to provide, translate and integrate the family history tool for genetic and treatable chronic conditions (for example, diabetes, coronary artery disease), newborn screening information and follow-up practice including just-in-time resources (HRSA/NCC ACTION sheets), genetic medicine, genomic information, and evidence-based clinical guidelines.
 - b. Implement interoperable systems that contain clinical guidelines, practice models, and care plans to improve services that address transition from pediatrics to adult care services and self-development of adolescents and young adults affected with developmental and genetic conditions.
 - c. Implement communication models for genetic and primary care co-management, such as, portable medical summary, patient portals or personal health records.
- 2) Contextually use the role of cultural competence and diversity in the widespread adoption of innovative outreach projects for the delivery of genetic clinical and education services for underserved and underrepresented groups, and assess and adjust to changing demographics of populations. Examples are:
- a. African American, Native American, Hispanic and Asian populations.
 - b. Hearing Impairment populations; partner with American Speech-Language-Hearing Association (ASHA) and The Center for Hearing and Speech.
- 3) Expand the pool of the genetic service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties and educators. Examples are:
- a. Nurses (home visiting nurses, nurse practitioners, nurse midwives, doulas and other childbirth educators).
 - b. Faculty and students at school-based systems and health care centers.
 - c. Nutritionists.
 - d. Occupational and physical therapists providers.
 - e. School-based systems and school health centers that serve children and youth with special needs.
- 4) Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services, for example:
- a. Partner with MCHB Title V Directors, other public health officials, and state insurance providers.
 - b. Provide education on the health and financial impact of heritable conditions in families.
 - c. Assist states with information and resources to improve the financing of screening, services and treatment.
 - d. Create a Learning Collaborative for the implementation of national newborn screening recommendations for heritable disorders.
 - e. Assist states with the development of public health policies and legislation for newborn screening and genetic services; including the addition of conditions to the Recommended Uniform Screening Panel (RUSP), recommended by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) and adopted by the HHS Secretary.
 - f. Support sharing of state health data integration and transparency to improve public health function.

- 5) Strengthen public-private partnerships, communication and collaboration among public health, individuals and their families, primary care providers, and genetic medicine, other subspecialty providers, and other entities. Examples are:
 - a. State public health programs for Maternal and Child Health (MCH), and Children with Youth with Special Health Care Needs (CYSHCN), Early Intervention (Part C), State Birth Defects Registries, and newborn screening and follow-up programs.
 - b. Screening and diagnostic laboratories for genetic conditions.
 - c. Federally-funded safety-net providers and other community organizations.
 - d. Federal agencies including Centers for Disease Control and Prevention (CDC), NIH National Institute of Child Health (NICHD), and the NIH Office of Rare Disease Research (ORDR).
 - e. Professional organizations - American Academy of Pediatrics (AAP), American Academy of Family Practice (AAFP), American College Of Medical Genetics (ACMG), Society of Inherited Metabolic Disorders (SIMD), Association of Public Health Laboratories (APHL), Association of Maternal and Child Health Programs (AMCHP), Association of University Centers for Disabilities (AUCD).
 - f. Consumer organizations - Genetic Alliance and Family Voices.

- 6) Collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices such as the Home Visiting Program, State MCHB Title V, Healthy Start, and other initiatives:
 - a. MCHB DSCSHN Genetic Services Branch (GSB): National Newborn Screening Clearinghouse; National Newborn Screening and Genetics Resources Center; Effective Follow-up in Newborn Screening; and Sickle Cell Disease Treatment Demonstration Program and National Coordinating Center; Sickle Cell Disease Newborn Screening Program National Coordinating and Evaluation Center; and National Hemophilia Program; Comprehensive Medical Care for Thalassaemia; and the Hemophilia Program.
 - b. MCHB DSCSHN Integrated Services Branch (ISB): National Centers for Family/Professional Partnerships; Medical Home Implementation; Catalyst - Health Insurance and Financing, Integrated Community Based Services, Health Care Transition Center; Cultural Competence; Hearing Assessment and Management; and State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorders.
 - c. MCHB DRTE: Leadership Education in Neurodevelopment and Other Disabilities (LEND); and LEND National Combating Autism Interdisciplinary Training Resource Center; and Autism Intervention Research Networks.

- 7) Improve insurance coverage policy and reimbursement of clinical genetic services for families, including genetic testing, medical food and formulas, and comprehensive and coordinated care.
 - a. Address populations and communities at risk of disparities in health and health care.
 - b. As health reform matures, promote and disseminate information to families on genetic services financing, legislation (Affordable Care Act), Federal and State options for insurance coverage, and include the benefits and barriers to coverage.
 - c. Intersect with Centers for Medicare and Medicaid Services (CMS).
 - d. Partner with major public and private health care insurance providers and programs; for example, State Medicaid and WIC, Health Management Organizations (HMOs, such as Kaiser Permanente).
 - e. Partner with other institutions and organizations that focus on health economic equality.

- 8) Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.
 - a. Integrate with public health surveillance systems, or hospital emergency information systems.
 - b. Develop clinical evidence-based guidelines.
 - c. Address privacy and HIPAA issues.
 - d. Partner with the ACMG Newborn Screening Translational Research Network (NBSTRN).

- 9) In the event of natural or other disasters, continue to address emergency preparedness with state laboratories and genetic centers for laboratory back-up and patient management and treatment, in cooperation with federal (for example, the Federal Emergency Management Agency (FEMA), local government and other assistance programs, and the Association of Public Health Laboratories (APHL).

- 10) Any other **PROGRAM PRIORITY** that addresses the needs of the region and the **PROGRAM GOALS**.

2. Background

The Regional Genetic and Newborn Screening Services Collaboratives: Heritable Disorders Program is authorized by the Public Health Service Act, §1109 (42 U.S.C. 300b-8), as amended by the Newborn Screening Saves Lives Act of 2008 (P.L. 110-204 and P.L. 110-237).

Prior Funding for the Regional Genetic and Newborn Screening Service Collaboratives

The Heritable Disorders Program was established to enhance, improve, or expand the ability of state and local public health agencies to provide screening, counseling, or health care services to newborns and children having or at risk for heritable disorders. Though authorized in 2000, in Fiscal Year 2004 Congress appropriated funds and HRSA/MCHB created an initiative to support the Heritable Disorders Program through a National Coordinating Center and seven (7) Regional Genetic and Newborn Screening Services Collaboratives. A regional approach was undertaken to address the challenges of the legislation, especially the geographic maldistribution of genetic subspecialist expertise to manage and treat individuals at risk and affected with heritable disorders identified through newborn screening.

Since 2004, a primary focus of the grant program was to ensure that affected individuals and their families are provided quality care and expertise in a medical home environment that enhances communication and collaboration between primary care, subspecialists and families. Regional Collaborative activities that have received national attention are highlighted below.

- Medical Home - care coordination, quality improvement, provider education, portable health care records, just-in-time/point of care ACTion sheets, a national NCC Transition Special Interest Group, and a NCC Medical Home Workgroup.
- Distance communication strategies (telemedicine) – education and clinical consultation, outreach clinics, a telemedicine teaching manual, and a NCC Telemedicine Workgroup.
- Emergency Preparedness - meetings for NBS laboratory back-up interstate sample exchange and drills, clinical follow-up protocols for genetics centers, public health laboratory and clinical table top exercise, and NCC-funded emergency preparedness experts.

- Newborn screening laboratory quality assurance - analytical laboratory test performance among states across the region, child testing technologies, laboratory quality assurance measures, and confirmatory testing guidelines.
- Long-term Follow-up (LTFU) - data set of public health measures, disease specific care plans and data collection, inborn errors of metabolism information system for clinical benefit and research, nutrition management guidelines, NCC Disease Specific Workgroup and NCC LTFU Workgroup.
- Regional genetic service plans completed.

Developed in 2007 by the NCC Evaluation Workgroup, the Evaluation of Regional Collaborative activity, December 1, 2009 - November 30, 2010 reports an overall increase in specific program outcome measures compared to the report on 2009-2010. Improvements were documented in the following areas:

- Increase in the percentage of states/territories in the region with collaborations facilitated by the Regional Collaborative between primary care providers (PCPs) and specialty (including genetic) providers to improve care coordination for people with heritable disorders
- Increase in the number of genetic services visits and NBS follow-up specialty visits provided to individuals/families through distance strategies implemented by the regional collaborative.
- Increase in the percentage of states/territories in the region that have received current materials or other assistance from the RC on emergency preparedness/contingency planning for newborn screening (NBS) and genetic services.
- Increase in the percentage of states/territories in the region that have evaluated and made recommendations on implementing the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommended Uniform Newborn Screening Panel.
- Increase in the percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with hearing loss through their state-sponsored newborn hearing screening programs.
- Increase in the percentage of states/territories in the region whose newborn screening (NBS) programs disseminate “just-in-time/point-of-care” information on specific heritable disorders to primary care providers (PCPs).
- Increase in the percentage of Regional Collaboratives that have completed a regional genetic services plan.

II. Award Information

1. Type of Award

Funding will be provided in the form of a grant.

2. Summary of Funding

This program will provide funding during federal fiscal years 2012–2016. Approximately \$4,200,000 is expected to be available annually to fund seven (7) grantees. Applicants may apply for a ceiling amount of up to \$600,000 per year. The project period is five (5) years: June 1, 2012 through May 31, 2017. Funding beyond the first year is dependent on the availability of appropriated funds for the Heritable

Disorders Program in subsequent fiscal years, grantee satisfactory performance, and a decision that continued funding is in the best interest of the Federal Government.

III. Eligibility Information

1. Eligible Applicants

Eligible applicants include: (1) a state or a political subdivision of a state; (2) a consortium of two or more states or political subdivisions of states; (3) a territory; (4) a health facility or program operated by or pursuant to a contract with or grant from the Indian Health Service; or (5) any other entity with appropriate expertise in newborn screening, as determined by the Secretary. Applicants that fail to show that they are based within the identified region it will serve and be part of a collaborative network of public health program entities responsible for genetic and/or newborn screening and services in all of the states and U.S. territories within that region will not be considered.

In addition, applicants must have significant familiarity and experience with multi-activities within the designated region that show communication and collaboration among: public health and community programs; genetic medicine, primary care and other subspecialty providers; genetic screening and testing laboratorians; and individuals at risk for or affected with heritable disorders and their families. **Applicants may NOT apply concurrently for grant funding as the primary applicant for both the National Coordinating Center (HRSA-12-139) and a Regional Genetic and Newborn Screening Service Collaborative (HRSA-12-138).** If an applicant does apply for both funding opportunities, both applications will be disqualified.

2. Cost Sharing/Matching

Matching or cost sharing is not required.

3. Other

Applications that exceed the ceiling amount will be considered non-responsive and will not be considered for funding under this announcement.

Any application that fails to satisfy the deadline requirements referenced in *Section IV.3* will be considered non-responsive and will not be considered for funding under this announcement.

Non-Supplantation

Grant funds shall be used to supplement and not supplant other federal, state, and local public funds provided for activities described in this funding opportunity announcement.

IV. Application and Submission Information

1. Address to Request Application Package

Application Materials and Required Electronic Submission Information

HRSA *requires* applicants for this funding opportunity announcement to apply electronically through Grants.gov. This robust registration and application process protects applicants against fraud and

ensures that only authorized representatives from an organization can submit an application. Applicants are responsible for maintaining these registrations, which should be completed well in advance of submitting your application. All applicants *must* submit in this manner unless they obtain a written exemption from this requirement in advance by the Director of HRSA's Division of Grants Policy. Applicants must request an exemption in writing from DGPWaivers@hrsa.gov, and provide details as to why they are technologically unable to submit electronically through the Grants.gov portal. Your email must include the HRSA announcement number for which you are seeking relief, the organization's DUNS number, the name, address, and telephone number of the organization and the name and telephone number of the Project Director as well as the Grants.gov Tracking Number (GRANTXXXX) assigned to your submission along with a copy of the "Rejected with Errors" notification you received from Grants.gov. **HRSA and its Digital Services Operation (DSO) will only accept paper applications from applicants that received prior written approval.** However, the application must still be submitted under the deadline. Suggestion: submit application to Grants.gov at least two days before the deadline to allow for any unforeseen circumstances.

Note: Central Contractor Registration (CCR) information must be updated at least every 12 months to remain active (for both grantees and sub-recipients). As of August 9, 2011, Grants.gov began rejecting submissions from applicants with expired CCR registrations. Although active CCR registration at time of submission is not a new requirement, this systematic enforcement will likely catch some applicants off guard. According to the CCR Website it can take 24 hours or more for updates to take effect, so ***check for active registration well before your grant deadline.***

An applicant can view their CCR Registration Status by visiting <http://www.bpn.gov/CCRSearch/Search.aspx> and searching by their organization's DUNS. The [CCR Website](#) provides user guides, renewal screen shots, FAQs and other resources you may find helpful.

Applicants that fail to allow ample time to complete registration with CCR and/or Grants.gov will not be eligible for a deadline extension or waiver of the electronic submission requirement.

All applicants are responsible for reading the instructions included in HRSA's *Electronic Submission User Guide*, available online at <http://www.hrsa.gov/grants/apply/userguide.pdf>. This Guide includes detailed application and submission instructions for both Grants.gov and HRSA's Electronic Handbooks. Pay particular attention to Sections 2 and 5 that provide detailed information on the competitive application and submission process.

Applicants are also responsible for reading the Grants.gov Applicant User Guide, available online at <http://www.grants.gov/assets/ApplicantUserGuide.pdf>. This Guide includes detailed information about using the Grants.gov system and contains helpful hints for successful submission.

Applicants must submit proposals according to the instructions in the Guide and in this funding opportunity announcement in conjunction with Application Form SF-424. The forms contain additional general information and instructions for applications, proposal narratives, and budgets. The forms and instructions may be obtained from the following site by:

- 1) Downloading from <http://www.grants.gov>, or
- 2) Contacting the HRSA Digital Services Operation (DSO) at: HRSADSO@hrsa.gov

Each funding opportunity contains a unique set of forms and only the specific forms package posted with an opportunity will be accepted for that opportunity. Specific instructions for preparing portions of the application that must accompany Application Form SF-424 appear in the “Application Format Requirements” section below.

2. Content and Form of Application Submission

Application Format Requirements

The total size of all uploaded files may not exceed the equivalent of 80 pages when printed by HRSA. The total file size may not exceed 10 MB. The 80-page limit includes the abstract, project and budget narratives, attachments, and letters of commitment and support. Standard forms are NOT included in the page limit. **We strongly urge you to print your application to ensure it does not exceed the 80-page limit. Do not reduce the size of the fonts or margins to save space. See the formatting instructions in Section 5 of the Electronic Submission User Guide referenced above. The 80-page limit will then be imposed.**

Applications must be complete, within the 80-page limit, within the 10 MB limit, and submitted prior to the deadline to be considered under this announcement.

Application Format

Applications for funding must consist of the following documents in the following order:

SF-424 Non-Construction – Table of Contents

-  It is mandatory to follow the instructions provided in this section to ensure that your application can be printed efficiently and consistently for review.
-  Failure to follow the instructions may make your application non-responsive. Non-responsive applications will not be considered under this funding opportunity announcement.
-  For electronic submissions, applicants only have to number the electronic attachment pages sequentially, resetting the numbering for each attachment, i.e., start at page 1 for each attachment. Do not attempt to number standard OMB approved form pages.
-  For electronic submissions, no Table of Contents is required for the entire application. HRSA will construct an electronic table of contents in the order specified.

| Application Section | Form Type | Instruction | HRSA/Program Guidelines |
|--|------------|---|--|
| Application for Federal Assistance (SF-424) | Form | Pages 1, 2 & 3 of the SF-424 face page. | Not counted in the page limit |
| Project Summary/Abstract | Attachment | Can be uploaded on page 2 of SF-424 - Box 15 | Required attachment. Counted in the page limit. Refer to the funding opportunity announcement for detailed instructions. |
| Additional Congressional District | Attachment | Can be uploaded on page 3 of SF-424 - Box 16 | As applicable to HRSA; not counted in the page limit. |
| Project Narrative Attachment Form | Form | Supports the upload of Project Narrative document | Not counted in the page limit. |
| Project Narrative | Attachment | Can be uploaded in Project Narrative Attachment form. | Required attachment. Counted in the page limit. Refer to the funding opportunity announcement for detailed instructions. Provide table of contents specific to this document only as the first page. |
| SF-424A Budget Information - Non-Construction Programs | Form | Pages 1–2 to support structured budget for the request of Non-construction related funds. | Not counted in the page limit. |
| Budget Narrative Attachment Form | Form | Supports the upload of Project Narrative document. | Not counted in the page limit. |
| Budget Narrative | Attachment | Can be uploaded in Budget Narrative Attachment form. | Required attachment. Counted in the page limit. Refer to the funding opportunity announcement for detailed instructions. |
| SF-424B Assurances - Non-Construction Programs | Form | Supports assurances for non-construction programs. | Not counted in the page limit. |
| Project/Performance Site Location(s) | Form | Supports primary and 29 additional sites in structured form. | Not counted in the page limit. |
| Additional Performance Site | Attachment | Can be uploaded in the SF-424 Performance | Not counted in the page limit. |

| Application Section | Form Type | Instruction | HRSA/Program Guidelines |
|--|------------|--|---|
| Location(s) | | Site Location(s) form. Single document with all additional site location(s) | |
| Disclosure of Lobbying Activities (SF-LLL) | Form | Supports structured data for lobbying activities. | Not counted in the page limit. |
| Other Attachments Form | Form | Supports up to 15 numbered attachments. This form only contains the attachment list. | Not counted in the page limit. |
| Attachment 1-15 | Attachment | Can be uploaded in Other Attachments form 1-15. | Refer to the attachment table provided below for specific sequence. Counted in the page limit. |

- 🔔 To ensure that attachments are organized and printed in a consistent manner, follow the order provided below. Note that these instructions may vary across programs.
- 🔔 Evidence of Non-Profit status and invention related documents, if applicable, must be provided in the other attachment form.
- 🔔 Additional supporting documents, if applicable, can be provided using the available rows. Do not use the rows assigned to a specific purpose in the program funding opportunity announcement.
- 🔔 Merge similar documents into a single document. Where several documents are expected in the attachment, ensure that you place a table of contents cover page specific to the attachment. The Table of Contents page will not be counted in the page limit.
- 🔔 Limit the file attachment name to under 50 characters. Do not use any special characters (e.g., %, /, #) or spacing in the file name or word separation. (The exception is the underscore (_) character.) Your attachment will be rejected by Grants.gov if you use special characters or attachment names greater than 50 characters.

| Attachment Number | Attachment Description (Program Guidelines) |
|-------------------|---|
| Attachment 1 | Relevant Maps, Charts, Tables, etc. |
| Attachment 2 | Job Descriptions for Key Personnel - Limit each to one page. |
| Attachment 3 | Biographical Sketches of Key Personnel listed in Attachment 2. Limit each sketch to two pages each. |
| Attachment 4 | Letters of Agreement, Memoranda of Understanding, and/or Description(s) of Proposed/Existing Contracts (project specific) |
| Attachment 5 | Two Charts: Project Organizational Chart and Administration Organization Chart of Agency or Institution. |
| Attachment 6 | Other Relevant Documents to include Letters of Support. |
| Attachment 7 | Work Plan Matrix and Logic Model |
| Attachment 8 | Fifth Year Budget. For year 5, submit a copy of Section B of the SF-424A. |
| Attachment 9 | Federally Negotiated Indirect Cost Rate Agreement (if applicable). |

Application Format

i. Application Face Page

Complete Application Form SF-424 provided with the application package. Prepare according to instructions provided in the form itself. Important note: enter the name of the **Project Director** in 8. f. for the SF-424 “Name and contact information of person to be contacted on matters involving this application.” If, for any reason, the Project Director will be out of the office, please ensure their email Out of Office Assistant is set so HRSA will be aware if any issues arise with the application and a timely response is required. For information pertaining to the Catalog of Federal Domestic Assistance, the CFDA Number is 93.110.

DUNS Number

All applicant organizations (and subrecipients of HRSA award funds) are required to have a Data Universal Numbering System (DUNS) number in order to apply for a grant or cooperative agreement from the Federal Government. The DUNS number is a unique nine-character identification number provided by the commercial company, Dun and Bradstreet. There is no charge to obtain a DUNS number. Information about obtaining a DUNS number can be found at <http://fedgov.dnb.com/webform> or call 1-866-705-5711. Please include the DUNS number in item 8c on the application face page. Applications **will not** be reviewed without a DUNS number. Note: A missing or incorrect DUNS number is the number one reason for applications being “Rejected for Errors” by Grants.gov. HRSA will not extend the deadline for applications with missing or incorrect DUNS number. Applicants should take care in entering the DUNS number in the application.

Additionally, the applicant organization (and any subrecipient of HRSA award funds) is required to register annually with the Federal Government’s Central Contractor Registration (CCR) in order to do electronic business with the Federal Government. CCR registration must be maintained with current, accurate information at all times during which an entity has an active award or an application or plan under consideration by HRSA. It is extremely important to verify that your CCR registration is active and your MPIN is current. Information about registering with the CCR can be found at <http://www.ccr.gov>.

ii. Table of Contents

The application should be presented in the order of the Table of Contents provided earlier. Again, for electronic applications no table of contents is necessary as it will be generated by the system. (Note: the Table of Contents will not be counted in the page limit.)

iii. Budget

Complete Application Form SF-424A Budget Information – Non-Construction Programs provided with the application package. Please complete Sections A, B, E, and F, and then provide a line item budget for each year of the project period. In Section A, use rows 1 - 4 to provide the budget amounts for the first four years of the project. Please enter the amounts in the “New or Revised Budget” column- not the “Estimated Unobligated Funds” column. In Section B Object Class Categories of the SF-424A, provide the object class category breakdown for the annual amounts specified in Section A. In Section B, use column (1) to provide category amounts for Year 1 and use columns (2) through (4) for subsequent budget years (up to four years). For year 5, please submit a copy of Section B of the SF-424A as Attachment 8.

iv. Budget Justification

Provide a narrative that explains the amounts requested for each line in the budget. The budget justification should specifically describe how each item will support the achievement of proposed objectives. The budget period is for ONE year. However, the applicant **must** submit one-year budgets for each of the subsequent budget periods within the requested project period (five years) at the time of application. Line item information must be provided to explain the costs entered in the SF-424A budget form. Be very careful about showing how each item in the “other” category is justified. For subsequent budget years, the justification narrative should highlight the changes from year one or clearly indicate that there are no substantive budget changes during the project period. The budget justification **MUST** be concise. Do NOT use the justification to expand the project narrative.

Budget for Multi-Year Award

This announcement is inviting applications for project periods up to five (5) years. Awards, on a competitive basis, will be for a one-year budget period; although the project period may be for up to five (5) years. Submission and HRSA approval of your Progress Report(s) and any other required submission or reports is the basis for the budget period renewal and release of subsequent year funds. Funding beyond the one-year budget period but within the five-year project period is subject to availability of funds, satisfactory progress of the awardee, and a determination that continued funding would be in the best interest of the Federal Government.

Include the following in the Budget Justification narrative:

Personnel Costs: Personnel costs should be explained by listing each staff member who will be supported from funds, name (if possible), position title, percentage of full-time equivalency, and annual salary. **The position of an Evaluator (part-time minimum) is required and is responsible for leadership of at least three activities: 1) development and implementation of a minimum of five (5) national project outcome measures as outlined in the Evaluation portion of the narrative (refer to x. Project Narrative, Evaluation and Technical Support Capacity) for annual Regional Collaborative evaluation; 2) work in concert with other Regional Collaborative Evaluators to develop additional program outcome measures for annual national evaluation, as requested; and 3) attend Quality Improvement Jumpstarts and/or Learning Collaboratives.**

Fringe Benefits: List the components that comprise the fringe benefit rate, for example health insurance, taxes, unemployment insurance, life insurance, retirement plans, and tuition reimbursement. The fringe benefits should be directly proportional to that portion of personnel costs that are allocated for the project.

Travel: List travel costs according to local and long distance travel. For local travel, the mileage rate, number of miles, reason for travel and staff member/consumers completing the travel should be outlined. The budget should also reflect the travel expenses associated with participating in meetings and other proposed trainings or workshops. **At least two key staff will be required to attend: joint meetings of the National Coordinating Center/Regional Collaborative Project Directors and HRSA staff in Washington, DC, and centrally located states; and at least two meetings per year of the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children in Washington, DC. The Evaluator will attend Quality Improvement**

Jumpstarts and/or Learning Collaboratives. HRSA may request other relevant travel during the fiscal year. In addition, consumer fellowship support may be provided for annual meetings that provide genetics education for consumers; for example, meetings of the Genetic Alliance in Washington, DC, and the American College of Medical Genetics.

Equipment: List equipment costs and provide justification for the need of the equipment to carry out the program's goals. Extensive justification and a detailed status of current equipment must be provided when requesting funds for the purchase of computers and furniture items that meet the definition of equipment (a unit cost of \$5,000 or more and a useful life of one or more years).

Supplies: List the items that the project will use. In this category, separate office supplies from medical and educational purchases. Office supplies could include paper, pencils, and the like; medical supplies are syringes, blood tubes, plastic gloves, etc., and educational supplies may be pamphlets and educational videotapes. Remember, they must be listed separately.

Contractual: Applicants are responsible for ensuring that their organization or institution has in place an established and adequate procurement system with fully developed written procedures for awarding and monitoring all contracts. Applicants must provide a clear explanation as to the purpose of each contract, how the costs were estimated, and the specific contract deliverables. Reminder: recipients must notify potential subrecipients that entities receiving subawards must be registered in the Central Contractor Registration (CCR) and provide the recipient with their DUNS number.

Other: Put all costs that do not fit into any other category into this category and provide an explanation of each cost in this category. In some cases, rent, utilities and insurance fall under this category if they are not included in an approved indirect cost rate. **Mini-projects are optional and must meet the purpose and goals of the project, approval by internal and outside peer review, and support the collaboration of two (2) or more states, institutions, organizations and/or other partners as proposed and endorsed by Letters of Support.**

Applicants may include the cost of access accommodations as part of their project's budget, including sign interpreters, plain language and health literate print materials in alternate formats (including Braille, large print, etc.); and cultural/linguistic competence modifications such as use of cultural brokers, translation or interpretation services at meetings, clinical encounters, and conferences, etc.

Indirect Costs: Indirect costs are those costs incurred for common or joint objectives which cannot be readily identified but are necessary to the operations of the organization, e.g., the cost of operating and maintaining facilities, depreciation, and administrative salaries. For institutions subject to OMB Circular A-21, the term "facilities and administration" is used to denote indirect costs. If an organization applying for an assistance award does not have an indirect cost rate, the applicant may wish to obtain one through HHS's Division of Cost Allocation (DCA). Visit DCA's website at: <http://rates.psc.gov/> to learn more about rate agreements, the process for applying for them, and the regional offices which negotiate them. **If an indirect cost is included in your budget, you must attach a copy of the federally negotiated cost rate agreement.**

If you have any questions about the indirect cost, contact the Grants Management Specialist, Linda Kittrell, LKittrell@hrsa.gov.

Unallowable Costs: See Section 5. Funding Restrictions

v. Staffing Plan and Personnel Requirements

Applicants must present a staffing plan and provide a justification for the plan that includes education and experience qualifications and rationale for the amount of time being requested for each staff position. Position descriptions that include the roles, responsibilities, and qualifications of proposed project staff must be included in Attachment 2. Biographical sketches for any key employed personnel that will be assigned to work on the proposed project must be included in Attachment 3. When applicable, biographical sketches should include training, language fluency and experience working with the cultural and linguistically diverse populations that are served by their programs.

vi. Assurances

Complete Application Form SF-424B Assurances – Non-Construction Programs provided with the application package.

vii. Certifications

Use the Certifications and Disclosure of Lobbying Activities Application Form provided with the application package.

viii. Project Abstract

Provide a summary of the application. Because the abstract is often distributed to provide information to the public and Congress, please prepare this so that it is clear, accurate, concise, and without reference to other parts of the application. It must include a brief description of the proposed project including the needs to be addressed, the proposed services, and the population group(s) to be served.

Please place the following at the top of the abstract:

- Project Title
- Applicant Organization Name
- Address
- Project Director Name
- Contact Phone Numbers (Voice, Fax)
- E-Mail Address
- Web Site Address, if applicable

Abstract content:

PROBLEM: Briefly (in one or two paragraphs) state the principal needs and problems which are addressed by the project.

GOAL(S) AND PRIORITIES: Identify the Program Goal(s) and Program Priorities for the project period. Typically, the goal is stated in a sentence or paragraph, and the objectives are presented in a numbered list.

METHODOLOGY: Describe the selected Program Priorities and activities used to attain the Program Goals and comment on innovation, cost, and other characteristics of the methodology. This section is usually several paragraphs long and describes the

activities which have been proposed or are being implemented to achieve the stated objectives. Lists with numbered items are sometimes used in this section as well.

COORDINATION: Describe the coordination planned with appropriate national, regional, state and/or local health agencies and/or organizations in the area(s) served by the project.

EVALUATION: Briefly describe the evaluation methods used to assess program outcomes and the effectiveness and efficiency of the project in attaining Goals and Priorities. This section is usually one or two paragraphs in length.

ANNOTATION: Provide a three- to- five-sentence description of your project that identifies the project's purpose, the needs and problems, which are addressed, the selected Priorities of the project, the activities, which will be used to attain the Goals and the materials which will be developed.

The project abstract must be single-spaced and limited to one page in length.

ix. Project Narrative

This section provides a comprehensive framework and description of all aspects of the proposed program. It should be succinct, self-explanatory and well organized so that reviewers can understand the proposed project.

Use the following section headers for the Narrative:

- ***INTRODUCTION***

This section should briefly describe the purpose of the proposed project.

- ***NEEDS ASSESSMENT***

This section outlines the needs of children, youth and adults in the proposed region and the states within the region, and the capacity within the region to meet those needs. The section should describe any maldistribution of genetic services and resources and the problems families and primary care providers have in accessing and utilizing those services/resources. The section should include specific underserved populations and populations in rural areas, and socio-cultural determinants of health and health disparities impacting the population or communities unmet. Data from regional and state and U.S. territory needs assessments, as well as demographic data, should be used and cited whenever possible to support the information provided. In addition, clearly identify relevant barriers and gaps in the service area that the project hopes to overcome, including the role of genetics in public health and gaps/strengths of the current system to address. This section should help reviewers understand the region, states and U.S. territories that will be served by the proposed project.

- ***METHODOLOGY***

Propose methods that will be used to meet the **PROGRAM GOALS** and **support each of the selected PROGRAM PRIORITIES**. As appropriate, include development of effective tools, technologies and strategies for ongoing staff training, outreach, collaborations, clear communication, and information sharing/dissemination with efforts to involve individuals at risk or affected with genetic conditions and their families and communities of culturally, linguistically, socio-economically and geographically diverse backgrounds. Describe the methodology to quantitatively and qualitatively evaluate outcomes of activities undertaken. Per the authorizing legislation, eligible applicants must

state how they have adopted and implemented, is in the process of adopting and implementing, or will use amounts received under such grant to adopt and implement the guidelines and recommendations of the Advisory Committee that are adopted by the Secretary and in effect at the time the grant is awarded. Link to Newborn Screening Saves Lives Act of 2008, <http://thomas.loc.gov/cgi-bin/query/D?c110:5:./temp/~c110AGfOgd::#>

▪ **WORK PLAN MATRIX**

For the **Work Plan Matrix**, describe the activities or steps that will be used to achieve each of the activities proposed during the entire project period in the Methodology section. Use a time line over the (five) 5-year grant cycle that includes each activity and identifies responsible staff, workgroup, and meaningful support and collaborations. In addition, a **logic model** for project activities and expected outcomes should also be clearly described.

▪ **RESOLUTION OF CHALLENGES**

Discuss challenges that are likely to be encountered in designing and implementing the activities described in the Work Plan, and approaches that will be used to resolve such challenges. Include policies relevant to the delivery, financing, and reimbursement of genetic services, as well as sustainability of activities.

▪ **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

Describe current experience, skills, and knowledge, including individuals on staff, materials published, and previous work of a similar nature.

Choose five (5) of the following Healthy People 2020 evaluation objectives OR provide five (5) measures that are nationally endorsed and list by whom (i.e. NQF, CMS or HEDIS, etc.) **to use for assessment of Regional Collaborative impact; region-wide or project specific assessment. Propose a method for collecting baseline and annual data and means to analyze the changes seen.**

From Healthy People 2020 objectives: <http://www.healthypeople.gov/2020/default.aspx>

- Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems. MICH-31 (line 107)
- Increase the number of Tribes, States and District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers. DH-2 (line 85)
- Increase the proportion of persons who report that their health care providers have satisfactory communication skills. HC/HIT-2 (line 27)
- (Developmental) Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health. HC/HIT-4 (line 32)
- Increase the proportion of children, including those with special health care needs, who have access to a medical home. MICH-30 (line 40)
- Increase the proportion of persons who report that their health care providers always involved them in decisions about their health care as much as they wanted. HC/HIT-3 (line 50)
- Increase the proportion of newborns who are screened for hearing loss by no later than age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months. ENT-VSL-1 (line 64)

- Increase the proportion of screen-positive children who receive follow-up testing within the recommended time period. MICH-32.2 (line 73)
- (Developmental) Increase the proportion of children with a diagnosed condition identified through newborn screening that have an annual assessment of services needed and received. MICH-32.3 (line 74)
- (Developmental) Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs. DH-8 (line 87)
- Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care. DH-5 (line 101)

▪ **ORGANIZATIONAL INFORMATION**

Provide information on the applicant organization’s current mission and structure, scope of current activities, and an organizational chart. Describe how these all contribute to the ability of the organization to conduct the program requirements and serve as an effective regional center. Demonstrate that the organization and administrative structures and processes are in place to allow for effective collaboration across all of the states and in the region it proposes to serve.

x. Program Specific Forms

1) Performance Standards for Special Projects of Regional or National Significance (SPRANS) and Other MCHB Discretionary Projects

The Health Resources and Services Administration (HRSA) has modified its reporting requirements for SPRANS projects, CISS projects, and other grant programs administered by the Maternal and Child Health Bureau (MCHB) to include national performance measures that were developed in accordance with the requirements of the Government Performance and Results Act (GPRA) of 1993 (Public Law 103-62). This Act requires the establishment of measurable goals for federal programs that can be reported as part of the budgetary process, thus linking funding decisions with performance. Performance measures for states have also been established under the Block Grant provisions of Title V of the Social Security Act, the MCHB’s authorizing legislation. Performance measures for other MCHB-funded grant programs have been approved by the Office of Management and Budget and are primarily based on existing or administrative data that projects should easily be able to access or collect. An electronic system for reporting these data elements has been developed and is now available.

*2) Performance Measures for the **Regional Genetic and Newborn Screening Services Collaboratives: Heritable Disorders Program** and Submission of Administrative Data*

To prepare successful applicants of their reporting requirements, the administrative forms and performance measures are presented in the appendices of this funding opportunity announcement. In summary, the forms and performance measures for this program are:

- Form 1, MCHB Project Budget Details
- Form 2, Project Funding Profile
- Form 4, Project Budget and Expenditures by Infrastructure Building

- Form 6, Abstract
- Form 7 (including section 7), Discretionary Grant Project Summary Data

Performance Measures

- PM03, The percentage of MCHB-funded projects submitting and publishing findings in peer-reviewed journals.
- PM07, The degree to which MCHB-funded programs ensure family, youth, and consumer participation in program and policy activities.
- PM10, The degree to which MCHB-funded programs have incorporated cultural and linguistic competence elements into their policies, guidelines, contracts and training.
- PM24, The degree to which MCHB-funded initiatives contribute to infrastructure development through core public health assessment, policy development and assurance functions.
- PM26, The extent of training and technical assistance (TA) provided and the degrees to which grantees have mechanisms in place to ensure quality in their training and TA activities.
- PM27, The degree to which grantees have mechanisms in place to ensure quality in the design, development, and dissemination of new information resources that they produce each year.
- PM33, The degree to which MCHB-funded initiatives work to promote sustainability of their programs or initiatives beyond the life of MCHB funding.
- PM37, The degree to which grantees have worked to increase the percentage of youth who have received services necessary to transition to all aspects of adult life, including adult health care, work, and independence.
- PM41, The degree to which grantees have assisted in developing, supporting, and promoting medical homes for MCH populations

Data Elements

- Products, Publications and Submissions Data Collection Form

xi. Attachments

Please provide the following items to complete the content of the application. Please note that these are supplementary in nature, and are not intended to be a continuation of the project narrative. Unless otherwise noted, attachments count toward the application page limit. **Each attachment must be clearly labeled.**

Attachment 1: Relevant Maps, Tables, Charts, etc.

Give further details about the proposal (e.g., Gantt or PERT charts, flow charts, etc.)

Attachment 2: Job Descriptions for Key Personnel

Limit each Job Description to **one (1) page**. Include the roles, responsibilities, and qualifications of proposed project staff.

Attachment 3: Biographical Sketches of Key Personnel

Include biographical sketches for persons occupying the key positions described in Attachment 2. **Limit each Biographical Sketch to two (2) pages**. If a biographical sketch is included for an identified individual who is not yet hired, include a letter of commitment from that person with the biographical sketch.

Attachment 4: Letters of Agreement, Memoranda of Understanding, and/or Description(s) of Proposed/Existing Contracts (project specific)

Provide any documents that describe working relationships between the applicant organization and other agencies and programs cited in the proposal. Documents that confirm actual or pending contractual agreements should clearly describe the roles of the subcontractors and any deliverable. Documents must be dated.

Attachment 5: Project Organizational Chart and Administration Chart

Provide two charts: A one-page figure that depicts the organizational structure of the project, including subcontractors and other significant collaborators; and a one-page administration chart to show where the grantee is located within the agency or institution.

Attachment 6: Other Relevant Documents to include Letters of Support.

Include any other documents that are relevant to the application, including letters of support. Letters of support must be dated. **Include key Letters of Support which specifically indicate a commitment to the project/program (in-kind services, dollars, staff, space, equipment, etc.) A single list of all Letters of Support is acceptable.**

Attachment 7: Logic Model and Work Plan Matrix.

Attachment 8: Fifth Year Budget

After using columns (1) through (4) of the SF-424A Section B for a five-year project period, the applicant will need to submit the budgets for year 5 as an attachment. They should use the SF-424A Section B.

Attachment 9: Federally Negotiated Indirect Cost Rate Agreement (if applicable)

Indirect costs are those costs incurred for common or joint objectives which cannot be readily identified but are necessary to the operations of the organization, e.g., the cost of operating and maintaining facilities, depreciation, and administrative salaries. For institutions subject to OMB Circular A-21, the term “facilities and administration” is used to denote indirect costs. If an organization applying for an assistance award does not have an indirect cost rate, the applicant may wish to obtain one through HHS’s Division of Cost Allocation (DCA). Visit DCA’s website at: <http://rates.psc.gov/> to learn more about rate agreements, the process for applying for them, and the regional offices which negotiate them. **If an indirect cost is included in your budget, you must attach a copy of the federally negotiated cost**

3. Submission Dates and Times

Application Due Date

The due date for applications under this funding opportunity announcement is *January 27, 2012 at 8:00 P.M. ET*. Applications completed online are considered formally submitted when the application has been successfully transmitted electronically by your organization’s Authorized Organization Representative (AOR) through Grants.gov and has been validated by Grants.gov on or before the deadline date and time.

Receipt acknowledgement: Upon receipt of an application, Grants.gov will send a series of email messages advising you of the progress of your application through the system. The first will confirm receipt in the system; the second will indicate whether the application has been

successfully validated or has been rejected due to errors; the third will be sent when the application has been successfully downloaded at HRSA; and the fourth will notify the applicant of the Agency Tracking Number assigned to the application.

The Chief Grants Management Officer (CGMO) or designee may authorize an extension of published deadlines when justified by circumstances such as natural disasters (e.g., floods or hurricanes) or other disruptions of services, such as a prolonged blackout. The CGMO or designee will determine the affected geographical area(s).

Late applications:

Applications which do not meet the criteria above are considered late applications and will not be considered in the current competition.

4. Intergovernmental Review

The Regional Genetic and Newborn Screening Services Collaborative: Heritable Disorders Program is not a program subject to the provisions of Executive Order 12372, as implemented by 45 CFR 100.

5. Funding Restrictions

Applicants responding to this announcement may request funding for a project period of up to five (5) years, at no more than \$600,000 per year. Awards to support projects beyond the first budget year will be contingent upon Congressional appropriation, satisfactory progress in meeting the project’s objectives, and a determination that continued funding would be in the best interest of the Federal Government.

Per legislation an eligible entity may not use amounts received to—

- (1) Provide cash payments to or on behalf of affected individuals;
- (2) Provide inpatient services;
- (3) Purchase land or make capital improvements to property; or
- (4) Provide for proprietary research or training.

6. Other Submission Requirements

As stated in Section IV.1, except in very rare cases HRSA will no longer accept applications in paper form. Applicants submitting for this funding opportunity are **required** to submit **electronically** through Grants.gov. To submit an application electronically, please use the APPLY FOR GRANTS section at <http://www.grants.gov> . When using Grants.gov you will be able to download a copy of the application package, complete it off-line, and then upload and submit the application via the Grants.gov site.

It is essential that your organization **immediately register** in Grants.gov and become familiar with the Grants.gov site application process. If you do not complete the registration process you will be unable to submit an application. The registration process can take up to one month.

To be able to successfully register in Grants.gov, it is necessary that you complete all of the following required actions:

- Obtain an organizational Data Universal Numbering System (DUNS) number

- Register the organization with Central Contractor Registration (CCR)
- Identify the organization’s E-Business Point of Contact (E-Biz POC)
- Confirm the organization’s CCR “Marketing Partner ID Number (M-PIN)” password
- Register and approve an Authorized Organization Representative (AOR)
- Obtain a username and password from the Grants.gov Credential Provider

Instructions on how to register, tutorials and FAQs are available on the Grants.gov web site at <http://www.grants.gov>. Assistance is also available 24 hours a day, 7 days a week (excluding federal holidays) from the Grants.gov help desk at support@grants.gov or by phone at 1-800-518-4726. Applicants should ensure that all passwords and registration are current well in advance of the deadline.

It is incumbent on applicants to ensure that the AOR is available to submit the application to HRSA by the published due date. HRSA will not accept submission or re-submission of incomplete, rejected, or otherwise delayed applications after the deadline. Therefore, you are urged to submit your application in advance of the deadline. If your application is rejected by Grants.gov due to errors, you must correct the application and resubmit it to Grants.gov before the deadline date and time. Deadline extensions will not be provided to applicants who do not correct errors and resubmit before the posted deadline.

If, for any reason, an application is submitted more than once prior to the application due date, HRSA will only accept the applicant’s last validated electronic submission prior to the application due date as the final and only acceptable submission of any competing application submitted to Grants.gov.

Tracking your application: It is incumbent on the applicant to track their application by using the Grants.gov tracking number (GRANTXXXXXXXX) provided in the confirmation email from Grants.gov. More information about tracking your application can be found at <https://apply07.grants.gov/apply/checkAppStatus.faces>. Be sure your application is validated by Grants.gov prior to the application deadline.

V. Application Review Information.

1. Review Criteria

Procedures for assessing the technical merit of applications have been instituted to provide for an objective review of applications and to assist the applicant in understanding the standards against which each application will be judged. Critical indicators have been developed for each review criterion to assist the applicant in presenting pertinent information related to that criterion and to provide the reviewer with a standard for evaluation. Review criteria are outlined below with specific detail and scoring points.

Review Criteria are used to review and rank applications. The *Regional Genetic and Newborn Screening Services Collaborative* has six (6) review criteria:

Criterion 1: NEED (10 points)

The extent to which the application demonstrates the problem and associated contributing factors to the problem. Include relevant barriers and gaps in the service area that the project hopes to

overcome.

- The extent to which the plan documents the characteristics of the region, states and U.S. territories to be served as they relate to the genetic service needs of the area. (5 points)
- The extent to which the plan demonstrates discussion of the gaps and barriers to genetic services within the region that the project proposes to overcome, especially the disparities among different socioeconomic, racial, ethnic, and rural groups. (5 points)

Criterion 2: RESPONSE (30 points)

Did the applicant identify, at a **MINIMUM, two (2) PROGRAM PRIORITIES**? Did the applicant assure how it will address the **authorizing legislation requirement related to newborn screening conditions as approved by the Secretary of Health and Human Services?** (Refer to ix. Project Narrative, Methodology, page 17.) **If the applicant does not meet both, then 0 POINTS awarded.**

- The extent to which the applicant responds to the “**Purpose**” and “**PROGRAM GOALS**” included in the “Funding Opportunity Description”; and specifically, the strength and support of the identified **PROGRAM PRIORITIES** and their activities. (12 points)
- The extent to which the plan proposes to overcome the gaps and barriers in genetic services especially for identified underserved and rural populations? (7 points)
- The extent to which the plan demonstrates that advanced education and clinical technologies are built into the activities, such as, evidence-based clinical guidelines, integrated tools, genetic medicine and primary care practice models, Health Information Technology (HIT), electronic medical records or portable health records, long distance telegenetics technology, and systems of data integration that reflect transparency. (7 points)
- The extent to which the plan demonstrates sufficient documentation of existing or developing partnerships that intersect with MCHB DSCSHN and DRTE programs. (Refer to Program Goals, Program Priority no. 5, page 4). (4 points).

Criterion 3: EVALUATIVE MEASURES (25 points)

The extent to which each national measure will sufficiently and effectively monitor and quantitatively evaluate the project outcomes over the 5-year grant period; and the extent to which the measures are attributed to the activity.

Five (5) points for each of the five established national measures proposed - as outlined in, (Refer to ix. Project Narrative, Evaluation and Technical Support Capacity, pages 17-18).

Criterion 4: IMPACT (10 points)

The extent of dissemination of project results and materials and/or the extent to which project results may be interregional or national in scope and/or degree to which the project activities are replicable and sustainable beyond the federal funding.

- The extent to which the applicant demonstrates the potential of the proposed scope of projects for interregional and national dissemination. (4 points)
- The extent to which the plan describes the effective promotion and dissemination of project outcome materials, data outcomes, and best practice models developed in the proposal. (3 points)
- The extent to which the plan demonstrates financing of projects beyond federal funding for sustainability. (3 points)

Criterion 5: RESOURCES/CAPABILITIES (15 points)

The extent to which project personnel are qualified by training, experience, education, and expertise in genetics medicine and/or public health to implement and carry out the project, as well as the capabilities of the applicant organization, and quality and availability of facilities, especially grant and financial management.

- The extent to which the applicant demonstrates the sufficient capability of key personnel to carry-out the proposed project, including administrative, evaluation, grant and fiscal management. (3 points)
- The extent to which there is a description of the Regional Collaborative and the roles, responsibilities, and relationships between the Regional Collaborative partners. (3points)
- The extent to which the plan demonstrates the sufficient involvement of individuals at risk or affected with heritable disorders and their families in the development, implementation and evaluation of proposed project goals, objectivities and activities. (3 points)
- The extent to which the plan demonstrates an increase in recruitment and participation by key state public health officials (for example, MCHB Title V Directors, and other state newborn screening and genetic service coordinators), genetic medicine providers and primary care providers in the development, implementation and evaluation of program goals, objectives and activities. (3 points)
- Is there an advisory body in place with appropriate expertise to provide guidance; and the extent to which the plan demonstrates the composition of the body, and its structure, mission, goal, and membership? (3 points)

Criterion 6: SUPPORT REQUESTED (10 points) - The reasonableness of the proposed budget in relation to the **PROGRAM GOALS** and **PROGRAM PRIORITIES**, the complexity of the activities, and the anticipated results.

- The extent to which the applicant demonstrates sufficient funding available for the organizational structure and processes necessary for the applicant to serve as an effective regional center; including facility contracting to host Regional Collaborative meetings. (3 points)
- The extent to which the plan demonstrates sufficient funding available to support the complexity of the activities including partner expertise, and is sustainability of those activities discussed. (3 points)
- The extent to which the plan demonstrates the availability of funds to support family involvement and special medical, translation and transportation needs. (2 points)
- The extent to which the plan demonstrates the availability of funds to provide travel support, as needed, to key staff and partners, state public health professionals, and genetics and primary care providers, to attend Regional Collaborative meetings, other HRSA required meetings, and to attend professional conferences to present Collaborative projects. (2 points)

2. Review and Selection Process

The Division of Independent Review is responsible for managing objective reviews within HRSA. Applications competing for federal funds receive an objective and independent review performed by a committee of experts qualified by training and experience in particular fields or disciplines related to the program being reviewed. In selecting review committee members, other factors in addition to training and experience may be considered to improve the balance of

the committee, e.g., geographic distribution. Each reviewer is screened to avoid conflicts of interest and is responsible for providing an objective, unbiased evaluation based on the review criteria noted above. The committee provides expert advice on the merits of each application to program officials responsible for final selections for award.

Applications that pass the initial HRSA eligibility screening will be reviewed and rated by a panel based on the program elements and review criteria presented in relevant sections of this program announcement. The review criteria are designed to enable the review panel to assess the quality of a proposed project and determine the likelihood of its success. The criteria are closely related to each other and are considered as a whole in judging the overall quality of an application.

3. Anticipated Announcement and Award Dates

It is anticipated that awards will be announced prior to the start date of June 1, 2012.

VI. Award Administration Information

1. Award Notices

Each applicant will receive written notification of the outcome of the objective review process, including a summary of the expert committee's assessment of the application's merits and weaknesses, and whether the application was selected for funding. Applicants who are selected for funding may be required to respond in a satisfactory manner to Conditions placed on their application before funding can proceed. Letters of notification do not provide authorization to begin performance.

The Notice of Award sets forth the amount of funds granted, the terms and conditions of the award, the effective date of the award, the budget period for which initial support will be given, the non-federal share to be provided (if applicable), and the total project period for which support is contemplated. Signed by the Grants Management Officer, it is sent to the applicant's Authorized Organization Representative, and reflects the only authorizing document. It will be sent prior to the start date of June 1, 2012.

2. Administrative and National Policy Requirements

Successful applicants must comply with the administrative requirements outlined in 45 CFR Part 74 [Uniform Administrative Requirements for Awards and Subawards to Institutions of Higher Education, Hospitals, Other Nonprofit Organizations, and Commercial Organizations](#) or 45 CFR Part 92 [Uniform Administrative Requirements For Grants And Cooperative Agreements to State, Local, and Tribal Governments](#), as appropriate.

HRSA grant and cooperative agreement awards are subject to the requirements of the HHS Grants Policy Statement (HHS GPS) that are applicable based on recipient type and purpose of award. This includes, as applicable, any requirements in Parts I and II of the HHS GPS that apply to the award. The HHS GPS is available at <http://www.hrsa.gov/grants/>. The general terms and conditions in the HHS GPS will apply as indicated unless there are statutory,

regulatory, or award-specific requirements to the contrary (as specified in the Notice of Award).

Cultural and Linguistic Competence

HRSA is committed to ensuring access to quality health care for all. Quality care means access to services, information, materials delivered by competent providers in a manner that factors in the language needs, cultural richness, and diversity of populations served. Quality also means that, where appropriate, data collection instruments used should adhere to culturally competent and linguistically appropriate norms. For additional information and guidance, refer to the National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS) published by HHS and available online at

<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>. Additional cultural competency and health literacy tools, resources and definitions are available online at <http://www.hrsa.gov/culturalcompetence> and <http://www.hrsa.gov/healthliteracy>.

Trafficking in Persons

Awards issued under this funding opportunity announcement are subject to the requirements of Section 106 (g) of the Trafficking Victims Protection Act of 2000, as amended (22 U.S.C. 7104). For the full text of the award term, go to <http://www.hrsa.gov/grants/trafficking.html>. If you are unable to access this link, please contact the Grants Management Specialist identified in this funding opportunity to obtain a copy of the Term.

Smoke-Free Workplace

The Public Health Service strongly encourages all award recipients to provide a smoke-free workplace and to promote the non-use of all tobacco products. Further, Public Law 103-227, the Pro-Children Act of 1994, prohibits smoking in certain facilities (or in some cases, any portion of a facility) in which regular or routine education, library, day care, health care or early childhood development services are provided to children.

Healthy People 2020

Healthy People 2020 is a national initiative led by HHS that sets priorities for all HRSA programs. The initiative has four overarching goals: (1) attain high-quality, longer lives free of preventable disease, disability, injury, and premature death; (2) achieve health equity, eliminate disparities, and improve the health of all groups; (3) create social and physical environments that promote good health for all; and (4) promote quality of life, healthy development, and healthy behaviors across all life stages. The program consists of over 40 topic areas, containing measurable objectives. HRSA has actively participated in the work groups of all the topic areas and is committed to the achievement of the Healthy People 2020 goals. More information about Healthy People 2020 may be found online at <http://www.healthypeople.gov/>.

National HIV/AIDS Strategy (NHAS)

The National HIV/AIDS Strategy (NHAS) has three primary goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. The NHAS states that more must be done to ensure that new prevention methods are identified and that prevention resources are more strategically deployed. Further, the NHAS recognizes the importance of early entrance into care for people living with HIV to protect their health and reduce their potential of transmitting the virus to others. HIV disproportionately affects people who have less access to prevention, care and treatment services and, as a result, often have poorer health outcomes. Therefore, the NHAS advocates adopting community-level

approaches to identify people who are HIV-positive but do not know their serostatus and reduce stigma and discrimination against people living with HIV.

To the extent possible, program activities should strive to support the three primary goals of the NHAS. As encouraged by the NHAS, programs should seek opportunities to increase collaboration, efficiency, and innovation in the development of program activities to ensure success of the NHAS. Programs providing direct services should comply with federally-approved guidelines for HIV Prevention and Treatment (see <http://www.aidsinfo.nih.gov/Guidelines/Default.aspx> as a reliable source for current guidelines). More information can also be found at <http://www.whitehouse.gov/administration/eop/onap/nhas>

Health IT

Health information technology (Health IT) provides the basis for improving the overall quality, safety and efficiency of the health delivery system. HRSA endorses the widespread and consistent use of health IT, which is the most promising tool for making health care services more accessible, efficient and cost effective for all Americans.

Related Health IT Resources:

- [Health Information Technology \(HHS\)](#)
- [What is Health Care Quality and Who Decides? \(AHRQ\)](#)

3. Reporting

The successful applicant under this funding opportunity announcement must comply with the following reporting and review activities:

a. Audit Requirements

Comply with audit requirements of Office of Management and Budget (OMB) Circular A-133. Information on the scope, frequency, and other aspects of the audits can be found on the Internet at http://www.whitehouse.gov/omb/circulars_default.

b. Payment Management Requirements

Submit a quarterly electronic Federal Financial Report (FFR) Cash Transaction Report via the Payment Management System. The report identifies cash expenditures against the authorized funds for the grant or cooperative agreement. The FFR Cash Transaction Reports must be filed within 30 days of the end of each calendar quarter. Failure to submit the report may result in the inability to access award funds. Go to <http://www.dpm.psc.gov> for additional information.

c. Status Reports

1) **Federal Financial Report.** The Federal Financial Report (SF-425) is required within 90 days of the end of each budget period. The report is an accounting of expenditures under the project that year. Financial reports must be submitted electronically through EHB. More specific information will be included in the Notice of Award.

2) **Progress Report(s).** The awardee must submit a progress report to HRSA on an annual basis. Submission and HRSA approval of your Progress Report(s) triggers the budget period renewal and release of subsequent year funds. This report has two

parts. The first part demonstrates grantee progress on program-specific goals. The second part collects core performance measurement data including performance measurement data to measure the progress and impact of the project. Further information will be provided in the award notice.

3) **Final Report(s).** A final report is due within 90 days after the project period ends. The final report collects program-specific goals and progress on strategies; core performance measurement data; impact of the overall project; the degree to which the grantee achieved the mission, goal and strategies outlined in the program; grantee objectives and accomplishments; barriers encountered; and responses to summary questions regarding the grantee's overall experiences over the entire project period. The final report must be submitted on-line by awardees in the Electronic Handbooks system at <https://grants.hrsa.gov/webexternal/home.asp>.

4) **Performance Report(s).** The Health Resources and Services Administration (HRSA) has modified its reporting requirements for SPRANS projects, CISS projects, and other grant programs administered by the Maternal and Child Health Bureau (MCHB) to include national performance measures that were developed in accordance with the requirements of the Government Performance and Results Act (GPRA) of 1993 (Public Law 103-62). This Act requires the establishment of measurable goals for federal programs that can be reported as part of the budgetary process, thus linking funding decisions with performance. Performance measures for states have also been established under the Block Grant provisions of Title V of the Social Security Act, the MCHB's authorizing legislation. Performance measures for other MCHB-funded grant programs have been approved by the Office of Management and Budget and are primarily based on existing or administrative data that projects should easily be able to access or collect.

(1) Performance Measures and Program Data

To prepare applicants for these reporting requirements, the designated performance measures for this program and other program data collection are presented in the appendices of this funding opportunity announcement.

(2) Performance Reporting

Successful applicants receiving grant funds will be required, within 120 days of the Notice of Award (NoA), to register in HRSA's Electronic Handbooks (EHBs) and electronically complete the program specific data forms that appear in the appendices of this funding opportunity announcement. This requirement entails the provision of budget breakdowns in the financial forms based on the grant award amount, the project abstract and other grant summary data as well as providing objectives for the performance measures.

Performance reporting is conducted for each grant year of the project period. Grantees will be required, within 120 days of the NoA, to enter HRSA's EHBs and complete the program specific forms. This requirement includes providing expenditure data, finalizing the abstract and grant summary data as well as finalizing indicators/scores for the performance measures.

(3) Project Period End Performance Reporting

Successful applicants receiving grant funding will be required, within 90 days from the end of the project period, to electronically complete the program specific data forms

that appear in the appendices of this funding opportunity announcement. The requirement includes providing expenditure data for the final year of the project period, the project abstract and grant summary data as well as final indicators/scores for the performance measures.

d. Transparency Act Reporting Requirements

New awards (“Type 1”) issued under this funding opportunity announcement are subject to the reporting requirements of the Federal Funding Accountability and Transparency Act (FFATA) of 2006 (Pub. L. 109–282), as amended by section 6202 of Public Law 110–252, and implemented by 2 CFR Part 170. Grant and cooperative agreement recipients must report information for each first-tier subaward of \$25,000 or more in federal funds and executive total compensation for the recipient’s and subrecipient’s five most highly compensated executives as outlined in Appendix A to 2 CFR Part 170 (FFATA details are available online at <http://www.hrsa.gov/grants/ffata.html>). Competing continuation awardees, etc. may be subject to this requirement and will be so notified in the Notice of Award.

VII. Agency Contacts

Applicants may obtain additional information regarding business, administrative, or fiscal issues related to this funding opportunity announcement by contacting:

Linda Kittrell
Grants Management Specialist
HRSA Division of Grants Management Operations, OFAM
Parklawn Building, Room 11A-02
5600 Fishers Lane
Rockville, MD 20857
Telephone: (301) 594-4461
Fax: (301) 594-6069
Email: LKittrell@hrsa.gov

Additional information related to the overall program issues and/or technical assistance regarding this funding announcement may be obtained by contacting:

Jill F. Shuger, Sc.M.
Project Officer
Genetic Services Branch, MCHB, HRSA
Parklawn Building, Room 18A-19
5600 Fishers Lane
Rockville, MD 20857
Telephone: (301) 443-3247
Fax: (301) 480-2312
Email: JShuger@hrsa.gov

Applicants may need assistance when working online to submit their application forms electronically. Applicants should always obtain a case number when calling for support. For

assistance with submitting the application in Grants.gov, contact Grants.gov 24 hours a day, seven days a week, excluding federal holidays at:

Grants.gov Contact Center

Telephone: 1-800-518-4726

E-mail: support@grants.gov

iPortal: <http://grants.gov/iportal>

VIII. Tips for Writing a Strong Application

A concise resource offering tips for writing proposals for HHS grants and cooperative agreements can be accessed online at:

<http://www.hhs.gov/asrt/og/grantinformation/apptips.html>.

Appendix A: MCHB Administrative Forms and Performance Measures

To prepare successful applicants for their future performance reporting requirements, the Administrative Forms and Performance Measures assigned to this MCHB program are presented below.

Administrative Forms:

- Form 1, MCHB Project Budget Details
- Form 2, Project Funding Profile
- Form 4, Project Budget and Expenditures for Infrastructure Building
- Form 6, MCH Abstract
- Form 7 (including section 7), Discretionary Grant Project Summary Data

Performance Measures:

- PM03, The percentage of MCHB-funded projects submitting and publishing findings in peer-reviewed journals.
- PM07, The degree to which MCHB-funded programs ensure family, youth, and consumer participation in program and policy activities.
- PM10, The degree to which MCHB-funded programs have incorporated cultural and linguistic competence elements into their policies, guidelines, contracts and training.
- PM24, The degree to which MCHB-funded initiatives contribute to infrastructure development through core public health assessment, policy development and assurance functions.
- PM26, The extent of training and technical assistance (TA) provided and the degrees to which grantees have mechanisms in place to ensure quality in their training and TA activities.
- PM27, The degree to which grantees have mechanisms in place to ensure quality in the design, development, and dissemination of new information resources that they produce each year.
- PM33, The degree to which MCHB-funded initiatives work to promote sustainability of their programs or initiatives beyond the life of MCHB funding.
- PM37, The degree to which grantees have worked to increase the percentage of youth who have received services necessary to transition to all aspects of adult life, including adult health care, work, and independence.
- PM41, The degree to which grantees have assisted in developing, supporting, and promoting medical homes for MCH populations
- Products, Publications and Submissions Data Collection Form

FORM 1
MCHB PROJECT BUDGET DETAILS FOR FY _____

| | | |
|-----------|---|----------|
| 1. | MCHB GRANT AWARD AMOUNT | \$ _____ |
| 2. | UNOBLIGATED BALANCE | \$ _____ |
| 3. | MATCHING FUNDS | \$ _____ |
| | (Required: Yes [] No [] If yes, amount) | |
| | A. Local funds | \$ _____ |
| | B. State funds | \$ _____ |
| | C. Program Income | \$ _____ |
| | D. Applicant/Grantee Funds | \$ _____ |
| | E. Other funds: _____ | \$ _____ |
| 4. | OTHER PROJECT FUNDS (Not included in 3 above) | \$ _____ |
| | A. Local funds | \$ _____ |
| | B. State funds | \$ _____ |
| | C. Program Income (Clinical or Other) | \$ _____ |
| | D. Applicant/Grantee Funds (includes in-kind) | \$ _____ |
| | E. Other funds (including private sector, e.g., Foundations) | \$ _____ |
| 5. | TOTAL PROJECT FUNDS (Total lines 1 through 4) | \$ _____ |
| 6. | FEDERAL COLLABORATIVE FUNDS | \$ _____ |
| | (Source(s) of additional Federal funds contributing to the project) | |
| | A. Other MCHB Funds (Do not repeat grant funds from Line 1) | |
| | 1) Special Projects of Regional and National Significance (SPRANS) | \$ _____ |
| | 2) Community Integrated Service Systems (CISS) | \$ _____ |
| | 3) State Systems Development Initiative (SSDI) | \$ _____ |
| | 4) Healthy Start | \$ _____ |
| | 5) Emergency Medical Services for Children (EMSC) | \$ _____ |
| | 6) Traumatic Brain Injury | \$ _____ |
| | 7) State Title V Block Grant | \$ _____ |
| | 8) Other: _____ | \$ _____ |
| | 9) Other: _____ | \$ _____ |
| | 10) Other: _____ | \$ _____ |
| | B. Other HRSA Funds | |
| | 1) HIV/AIDS | \$ _____ |
| | 2) Primary Care | \$ _____ |
| | 3) Health Professions | \$ _____ |
| | 4) Other: _____ | \$ _____ |
| | 5) Other: _____ | \$ _____ |
| | 6) Other: _____ | \$ _____ |
| | C. Other Federal Funds | |
| | 1) Center for Medicare and Medicaid Services (CMS) | \$ _____ |
| | 2) Supplemental Security Income (SSI) | \$ _____ |
| | 3) Agriculture (WIC/other) | \$ _____ |
| | 4) Administration for Children and Families (ACF) | \$ _____ |
| | 5) Centers for Disease Control and Prevention (CDC) | \$ _____ |
| | 6) Substance Abuse and Mental Health Services Administration (SAMHSA) | \$ _____ |
| | 7) National Institutes of Health (NIH) | \$ _____ |
| | 8) Education | \$ _____ |
| | 9) Bioterrorism | \$ _____ |
| | 10) Other: _____ | \$ _____ |

| | | | |
|---|-------|-------|----|
| 11) Other: | _____ | _____ | \$ |
| 12) Other | _____ | _____ | \$ |
| 7. TOTAL COLLABORATIVE FEDERAL FUNDS | | _____ | \$ |

**INSTRUCTIONS FOR COMPLETION OF FORM 1
MCH BUDGET DETAILS FOR FY _____**

- Line 1. Enter the amount of the Federal MCHB grant award for this project.
- Line 2. Enter the amount of carryover (e.g, unobligated balance) from the previous year's award, if any. New awards do not enter data in this field, since new awards will not have a carryover balance.
- Line 3. If matching funds are required for this grant program list the amounts by source on lines 3A through 3E as appropriate. Where appropriate, include the dollar value of in-kind contributions.
- Line 4. Enter the amount of other funds received for the project, by source on Lines 4A through 4E, specifying amounts from each source. Also include the dollar value of in-kind contributions.
- Line 5. Displays the sum of lines 1 through 4.
- Line 6. Enter the amount of other Federal funds received on the appropriate lines (A.1 through C.12) **other** than the MCHB grant award for the project. Such funds would include those from other Departments, other components of the Department of Health and Human Services, or other MCHB grants or contracts.
- Line 6C.1. Enter only project funds from the Center for Medicare and Medicaid Services. Exclude Medicaid reimbursement, which is considered Program Income and should be included on Line 3C or 4C.
- If lines 6A.8-10, 6B .4-6, or 6C.10-12 are utilized, specify the source(s) of the funds in the order of the amount provided, starting with the source of the most funds. .
- Line 7. Displays the sum of lines in 6A.1 through 6C.12.

**FORM 2
 PROJECT FUNDING PROFILE**

| | <u>FY</u> | | <u>FY</u> | | <u>FY</u> | | <u>FY</u> | | <u>FY</u> | |
|--|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| | <u>Budgeted</u> | <u>Expended</u> |
| 1 <u>MCHB Grant Award Amount</u> <i>Line 1, Form 2</i> | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| 2 <u>Unobligated Balance</u> <i>Line 2, Form 2</i> | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| 3 <u>Matching Funds (If required)</u> <i>Line 3, Form 2</i> | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| 4 <u>Other Project Funds</u> <i>Line 4, Form 2</i> | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| 5 <u>Total Project Funds</u> <i>Line 5, Form 2</i> | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| 6 <u>Total Federal Collaborative Funds</u> <i>Line 7, Form 2</i> | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ | \$ _____ |

**INSTRUCTIONS FOR THE COMPLETION OF FORM 2
PROJECT FUNDING PROFILE**

Instructions:

Complete all required data cells. If an actual number is not available, use an estimate. Explain all estimates in a note.

The form is intended to provide funding data at a glance on the estimated budgeted amounts and actual expended amounts of an MCH project.

For each fiscal year, the data in the columns labeled Budgeted on this form are to contain the same figures that appear on the Application Face Sheet (for a non-competing continuation) or the Notice of Grant Award (for a performance report). The lines under the columns labeled Expended are to contain the actual amounts expended for each grant year that has been completed.

FORM 4
PROJECT BUDGET AND EXPENDITURES
By Types of Services

| <u>TYPES OF SERVICES</u> | FY _____ | | FY _____ | |
|---|-----------------|-----------------|-----------------|-----------------|
| | <u>Budgeted</u> | <u>Expended</u> | <u>Budgeted</u> | <u>Expended</u> |
| I. <u>Direct Health Care Services</u> (Basic Health Services and Health Services for CSHCN.) | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| II. <u>Enabling Services</u> (Transportation, Translation, Outreach, Respite Care, Health Education, Family Support Services, Purchase of Health Insurance, Case Management, and Coordination with Medicaid, WIC and Education.) | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| III. <u>Population-Based Services</u> (Newborn Screening, Lead Screening, Immunization, Sudden Infant Death Syndrome Counseling, Oral Health, Injury Prevention, Nutrition, and Outreach/Public Education.) | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| IV. <u>Infrastructure Building Services</u> (Needs Assessment, Evaluation, Planning, Policy Development, Coordination, Quality Assurance, Standards Development, Monitoring, Training, Applied Research, Systems of Care, and Information Systems.) | \$ _____ | \$ _____ | \$ _____ | \$ _____ |
| V. <u>TOTAL</u> | \$ _____ | \$ _____ | \$ _____ | \$ _____ |

**INSTRUCTIONS FOR THE COMPLETION OF FORM 4
PROJECT BUDGET AND EXPENDITURES BY TYPES OF SERVICES**

Complete all required data cells for all years of the grant. If an actual number is not available, make an estimate. Please explain all estimates in a note. Administrative dollars should be allocated to the appropriate level(s) of the pyramid on lines I, II, III or IV. If an estimate of administrative funds use is necessary, one method would be to allocate those dollars to Lines I, II, III and IV at the same percentage as program dollars are allocated to Lines I through IV.

Note: Lines I, II and III are for projects providing services. If grant funds are used to build the infrastructure for direct care delivery, enabling or population-based services, these amounts should be reported in Line IV (i.e., building data collection capacity for newborn hearing screening).

Line I Direct Health Care Services - enter the budgeted and expended amounts for the appropriate fiscal year completed and budget estimates only for all other years.

Direct Health Care Services are those services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room which may include primary care physicians, registered dietitians, public health or visiting nurses, nurses certified for obstetric and pediatric primary care, medical social workers, nutritionists, dentists, sub-specialty physicians who serve children with special health care needs, audiologists, occupational therapists, physical therapists, speech and language therapists, specialty registered dietitians. Basic services include what most consider ordinary medical care, inpatient and outpatient medical services, allied health services, drugs, laboratory testing, x-ray services, dental care, and pharmaceutical products and services. State Title V programs support - by directly operating programs or by funding local providers - services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and sub-specialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

Line II Enabling Services - enter the budgeted and expended amounts for the appropriate fiscal year completed and budget estimates only for all other years.

Enabling Services allow or provide for access to and the derivation of benefits from, the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of with Medicaid, WIC and educations. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, the enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition and social work.

Line III Population-Based Services - enter the budgeted and expended amounts for the appropriate fiscal year completed and budget estimates only for all other years.

Population Based Services are preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

Line IV Infrastructure Building Services - enter the budgeted and expended amounts for the appropriate fiscal year completed and budget estimates only for all other years.

Infrastructure Building Services are the base of the MCH pyramid of health services and form its foundation. They are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems and resources including development and maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the development of systems of care it should be assured that the systems are family centered, community based and culturally competent.

Line V Total – Displays the total amounts for each column, budgeted for each year and expended for each year completed.

FORM 6
MATERNAL & CHILD HEALTH DISCRETIONARY GRANT
PROJECT ABSTRACT
FOR FY ____

PROJECT: _____

I. PROJECT IDENTIFIER INFORMATION

1. Project Title:
2. Project Number:
3. E-mail address:

II. BUDGET

1. MCHB Grant Award \$ _____
(Line 1, Form 2)
2. Unobligated Balance \$ _____
(Line 2, Form 2)
3. Matching Funds (if applicable) \$ _____
(Line 3, Form 2)
4. Other Project Funds \$ _____
(Line 4, Form 2)
5. Total Project Funds \$ _____
(Line 5, Form 2)

III. TYPE(S) OF SERVICE PROVIDED (Choose all that apply)

- Direct Health Care Services
- Enabling Services
- Population-Based Services
- Infrastructure Building Services

IV. PROJECT DESCRIPTION OR EXPERIENCE TO DATE

- A. Project Description
1. Problem (in 50 words, maximum):

 2. Goals and Objectives: (List up to 5 major goals and time-framed objectives per goal for the project)
 - Goal 1:
 - Objective 1:
 - Objective 2:
 - Goal 2:
 - Objective 1:
 - Objective 2:
 - Goal 3:
 - Objective 1:
 - Objective 2:

- Goal 4:
 - Objective 1:
 - Objective 2:
- Goal 5:
 - Objective 1:
 - Objective 2:

3. Activities planned to meet project goals

4. Specify the primary *Healthy People 2010* objectives(s) (up to three) which this project addresses:
 - a.
 - b.
 - c.

5. Coordination (List the State, local health agencies or other organizations involved in the project and their roles)

6. Evaluation (briefly describe the methods which will be used to determine whether process and outcome objectives are met)

- B. Continuing Grants ONLY
1. Experience to Date (For continuing projects ONLY):

2. Website URL and annual number of hits

V. KEY WORDS

VI. ANNOTATION

INSTRUCTIONS FOR THE COMPLETION OF FORM 6 PROJECT ABSTRACT

NOTE: All information provided should fit into the space provided in the form. The completed form should be no more than 3 pages in length. Where information has previously been entered in forms 1 through 5, the information will automatically be transferred electronically to the appropriate place on this form.

Section I – Project Identifier Information

Project Title: Displays the title for the project.

Project Number: Displays the number assigned to the project (e.g., the grant number)

E-mail address: Displays the electronic mail address of the project director

Section II – Budget - These figures will be transferred from Form 1, Lines 1 through 5.

Section III - Types of Services

Indicate which type(s) of services your project provides, checking all that apply.

Section IV – Program Description OR Current Status (DO NOT EXCEED THE SPACE PROVIDED)

A. New Projects only are to complete the following items:

1. A brief description of the project and the problem it addresses, such as preventive and primary care services for pregnant women, mothers, and infants; preventive and primary care services for children; and services for Children with Special Health Care Needs.
2. Provide up to 5 goals of the project, in priority order. Examples are: To reduce the barriers to the delivery of care for pregnant women, to reduce the infant mortality rate for minorities and “services or system development for children with special healthcare needs.” MCHB will capture annually every project’s top goals in an information system for comparison, tracking, and reporting purposes; you must list at least 1 and no more than 5 goals. For each goal, list the two most important objectives. The objective must be specific (i.e., decrease incidence by 10%) and time limited (by 2005).
3. Displays the primary Healthy people 2010 goal(s) that the project addresses.
4. Describe the programs and activities used to attain the goals and objectives, and comment on innovation, cost, and other characteristics of the methodology, proposed or are being implemented. Lists with numbered items can be used in this section.
5. Describe the coordination planned and carried out, in the space provided, if applicable, with appropriate State and/or local health and other agencies in areas(s) served by the project.
6. Briefly describe the evaluation methods that will be used to assess the success of the project in attaining its goals and objectives.

B. For continuing projects ONLY:

1. Provide a brief description of the major activities and accomplishments over the past year (not to exceed 200 words).
2. Provide website and number of hits annually, if applicable.

Section V – Key Words

Provide up to 10 key words to describe the project, including populations served. Choose key words from the included list.

Section VI – Annotation

Provide a three- to five-sentence description of your project that identifies the project’s purpose, the needs and problems, which are addressed, the goals and objectives of the project, the activities, which will be used to attain the goals, and the materials, which will be developed.

FORM 7
DISCRETIONARY GRANT PROJECT
SUMMARY DATA

- 1. Project Service Focus**
 Urban/Central City Suburban Metropolitan Area (city & suburbs)
 Rural Frontier Border (US-Mexico)

- 2. Project Scope**
 Local Multi-county State-wide
 Regional National

- 3. Grantee Organization Type**
 State Agency
 Community Government Agency
 School District
 University/Institution Of Higher Learning (Non-Hospital Based)
 Academic Medical Center
 Community-Based Non-Governmental Organization (Health Care)
 Community-Based Non-Governmental Organization (Non-Health Care)
 Professional Membership Organization (Individuals Constitute Its Membership)
 National Organization (Other Organizations Constitute Its Membership)
 National Organization (Non-Membership Based)
 Independent Research/Planning/Policy Organization
 Other _____

- 4. Project Infrastructure Focus (from MCH Pyramid) if applicable**
 Guidelines/Standards Development And Maintenance
 Policies And Programs Study And Analysis
 Synthesis Of Data And Information
 Translation Of Data And Information For Different Audiences
 Dissemination Of Information And Resources
 Quality Assurance
 Technical Assistance
 Training
 Systems Development
 Other

5. Demographic Characteristics of Project Participants

Indicate the service level:

| | |
|--|---|
| <input type="checkbox"/> Direct Health Care Services | <input type="checkbox"/> Population-Based Services |
| <input type="checkbox"/> Enabling Services | <input type="checkbox"/> Infrastructure Building Services |

| | RACE (Indicate all that apply) | | | | | | | ETHNICITY | | | | |
|--|----------------------------------|-------|---------------------------|---|-------|--------------------|------------|-----------|--------------------|------------------------|------------|-------|
| | American Indian or Alaska Native | Asian | Black or African American | Native Hawaiian or Other Pacific Islander | White | More than One Race | Unrecorded | Total | Hispanic or Latino | Not Hispanic or Latino | Unrecorded | Total |
| Pregnant Women (All Ages) | | | | | | | | | | | | |
| Infants <1 year | | | | | | | | | | | | |
| Children and Youth 1 to 25 years | | | | | | | | | | | | |
| CSHCN Infants <1 year | | | | | | | | | | | | |
| CSHCN Children and Youth 1 to 25 years | | | | | | | | | | | | |
| Women 25+ years | | | | | | | | | | | | |
| Men 25+ | | | | | | | | | | | | |
| TOTALS | | | | | | | | | | | | |

6. Clients' Primary Language(s)

7. Resource/TA and Training Centers ONLY

Answer all that apply.

- a. Characteristics of Primary Intended Audience(s)
 - Policy Makers/Public Servants
 - Consumers
- Providers/Professionals
- b. Number of Requests Received/Answered: _____/_____
- c. Number of Continuing Education credits provided: _____
- d. Number of Individuals/Participants Reached: _____
- e. Number of Organizations Assisted: _____
- f. Major Type of TA or Training Provided:
 - continuing education courses,
 - workshops,
 - on-site assistance,
 - distance learning classes
 - other

INSTRUCTIONS FOR THE COMPLETION OF FORM 7 PROJECT SUMMARY

Section 1 – Project Service Focus

Select all that apply

Section 2 – Project Scope

Choose the one that best applies to your project.

Section 3 – Grantee Organization Type

Choose the one that best applies to your organization.

Section 4 – Project Infrastructure Focus

If applicable, choose all that apply.

Section 5 – Demographic Characteristics of Project Participants

Indicate the service level for the grant program. Multiple selections may be made. Infrastructure cannot be selected by itself; it must be selected with another service level. Please fill in each of the cells as appropriate.

Direct Health Care Services are those services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room which may include primary care physicians, registered dietitians, public health or visiting nurses, nurses certified for obstetric and pediatric primary care, medical social workers, nutritionists, dentists, sub-specialty physicians who serve children with special health care needs, audiologists, occupational therapists, physical therapists, speech and language therapists, specialty registered dietitians. Basic services include what most consider ordinary medical care, inpatient and outpatient medical services, allied health services, drugs, laboratory testing, x-ray services, dental care, and pharmaceutical products and services. State Title V programs support - by directly operating programs or by funding local providers - services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and sub-specialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

Enabling Services allow or provide for access to and the derivation of benefits from, the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of with Medicaid, WIC and educations. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, the enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition and social work.

Population Based Services are preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

Infrastructure Building Services are the base of the MCH pyramid of health services and form its foundation. They are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems and resources including development and maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the

development of systems of care it should be assured that the systems are family centered, community based and culturally competent.

Section 6 – Clients Primary Language(s)

Indicate which languages your clients speak as their primary language, other than English, for the data provided in Section 6. List up to three languages.

Section 7 – Resource/TA and Training Centers (Only)

Answer all that apply.

03 PERFORMANCE MEASURE

The percentage of MCHB-funded projects submitting and publishing findings in peer-reviewed journals.

Goal 1: Provide National Leadership for MCHB (Strengthen the MCH knowledge base and support scholarship within the MCH community)

Level: Grantee

Category: Information Dissemination

GOAL

To increase the number of MCHB-funded research projects that publish in peer-reviewed journals.

MEASURE

The percent of MCHB-funded projects submitting articles and publishing findings in peer-reviewed journals.

DEFINITION

Numerator: Number of projects (current and completed within the past three years) that have submitted articles for review by refereed journals.

Denominator: Total number of current projects and projects that have been completed within the past three years.

And

Numerator: Number of projects (current and completed within the past 3 years) that have published articles in peer reviewed journals

Denominator: Total number of current projects and projects that have been completed within the past three years.

Units: 100 **Text:** Percent

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Goal 1: Improve access to comprehensive, high-quality health care services (Objectives 1.1-1.16).

DATA SOURCE(S) AND ISSUES

Attached data collection form will be sent annually to grantees during their funding period and three years after the funding period ends. Some preliminary information may be gathered from mandated project final reports

SIGNIFICANCE

To be useful, the latest evidence-based, scientific knowledge must reach professionals who are delivering services, developing programs and making policy. Peer reviewed journals are considered one of the best methods for distributing new knowledge because of their wide circulation and rigorous standard of review.

DATA COLLECTION FORM FOR DETAIL SHEET #03

Please use the space provided for notes to detail the data source and year of data used.

Number of articles submitted for review by refereed journals but not yet published in this reporting year

Number of articles published in peer-reviewed journals this reporting year

NOTES/COMMENTS:

07 PERFORMANCE MEASURE

The degree to which MCHB-funded programs ensure family, youth, and consumer participation in program and policy activities.

Goal 1: Provide National Leadership for MCHB (Promote family participation in care)

Level: Grantee

Category: Family/Youth/Consumer Participation

GOAL

To increase family/youth/consumer participation in MCHB programs.

MEASURE

The degree to which MCHB-funded programs ensure family/youth/consumer participation in program and policy activities.

DEFINITION

Attached is a checklist of eight elements that demonstrate family participation, including an emphasis on family-professional partnerships and building leadership opportunities for families and consumers in MCHB programs. Please check the degree to which the elements have been implemented.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Objective 16.23. Increase the proportion of Territories and States that have service systems for Children with Special Health Care Needs to 100 percent.

DATA SOURCE(S) AND ISSUES

Attached data collection form is to be completed by grantees.

SIGNIFICANCE

Over the last decade, policy makers and program administrators have emphasized the central role of families and other consumers as advisors and participants in policy-making activities. In accordance with this philosophy, MCHB is facilitating such partnerships at the local, State and national levels.

Family/professional partnerships have been incorporated into the MCHB Block Grant Application, the MCHB strategic plan. Family/professional partnerships are a requirement in the Omnibus Budget Reconciliation Act of 1989 (OBRA '89) and part of the legislative mandate that health programs supported by Maternal and Child Health Bureau (MCHB) Children with Special Health Care Needs (CSHCN) provide and promote family centered, community-based, coordinated care.

DATA COLLECTION FORM FOR DETAIL SHEET #07

Using a scale of 0-3, please rate the degree to which the grant program has included families, youth, and consumers into their program and planning activities. Please use the space provided for notes to describe activities related to each element and clarify reasons for score.

| 0 | 1 | 2 | 3 | Element |
|---|---|---|---|---|
| | | | | 1. Family members/youth/consumers participate in the planning, implementation and evaluation of the program's activities at all levels, including strategic planning, program planning, materials development, program activities, and performance measure reporting. |
| | | | | 2. Culturally diverse family members/youth/consumers facilitate the program's ability to meet the needs of the populations served. |
| | | | | 3. Family members/youth/consumers are offered training, mentoring, and opportunities to lead advisory committees or task forces. |
| | | | | 4. Family members/youth/consumers who participate in the program are compensated for their time and expenses. |
| | | | | 5. Family members/youth/consumers participate on advisory committees or task forces to guide program activities. |
| | | | | 6. Feedback on policies and programs is obtained from families/youth/consumers through focus groups, feedback surveys, and other mechanisms as part of the project's continuous quality improvement efforts. |
| | | | | 7. Family members/youth/consumers work with their professional partners to provide training (pre-service, in-service and professional development) to MCH/CSHCN staff and providers. |
| | | | | 8. Family /youth/consumers provide their perspective to the program as paid staff or consultants. |

- 0=Not Met
- 1=Partially Met
- 2=Mostly Met
- 3=Completely Met

Total the numbers in the boxes (possible 0-24 score) _____

NOTES/COMMENTS:

10 PERFORMANCE MEASURE

**Goal 2: Eliminate Health Barriers & Disparities
(Develop and promote health services and
systems of care designed to eliminate disparities
and barriers across MCH populations)**

Level: Grantee

Category: Cultural Competence

The degree to which MCHB-funded programs have incorporated cultural and linguistic competence elements into their policies, guidelines, contracts and training.

GOAL

To increase the number of MCHB-funded programs that have integrated cultural and linguistic competence into their policies, guidelines, contracts and training.

MEASURE

The degree to which MCHB-funded programs have incorporated cultural and linguistic competence elements into their policies, guidelines, contracts and training.

DEFINITION

Attached is a checklist of 10 elements that demonstrate cultural and linguistic competency. Please check the degree to which the elements have been implemented. The answer scale for the entire measure is 0-30. Please keep the completed checklist attached.

Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. 'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. (Adapted from Cross, 1989; sited from DHHS Office of Minority Health--
<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=11>)

Linguistic competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Linguistic competency requires organizational and provider capacity to respond effectively to the health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to

support this capacity. (Goode, T. and W. Jones, 2004. National Center for Cultural Competence; <http://www.ncccurricula.info/linguisticcompetence.html>)

Cultural and linguistic competency is a process that occurs along a developmental continuum. A culturally and linguistically competent program is characterized by elements including the following: written strategies for advancing cultural competence; cultural and linguistic competency policies and practices; cultural and linguistic competence knowledge and skills building efforts; research data on populations served according to racial, ethnic, and linguistic groupings; participation of community and family members of diverse cultures in all aspects of the program; faculty and other instructors are racially and ethnically diverse; faculty and staff participate in professional development activities related to cultural and linguistic competence; and periodic assessment of trainees' progress in developing cultural and linguistic competence.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to the following HP2010 Objectives:

16.23: Increase the proportion of States and jurisdictions that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239.

23.9: (Developmental) Increase the proportion of schools for public health workers that integrate into their curricula specific content to develop competency in the essential public health services.

23.11:(Developmental) Increase the proportion of State and local public health agencies that meet national performance standards for essential public health services.

23.15: (Developmental) Increase the proportion of Federal, Tribal, State, and local jurisdictions that review and evaluate the extent to which their statutes, ordinances, and bylaws assure the delivery of essential public health services.

DATA SOURCE(S) AND ISSUES

Attached data collection form is to be completed by grantees.

There is no existing national data source to measure the extent to which MCHB supported programs have incorporated cultural competence elements into their policies, guidelines, contracts and training.

SIGNIFICANCE

Over the last decade, researchers and policymakers have emphasized the central influence of cultural

values and cultural/linguistic barriers: health seeking behavior, access to care, and racial and ethnic disparities. In accordance with these concerns, cultural competence objectives have been: (1) incorporated into the MCHB strategic plan; and (2) in guidance materials related to the Omnibus Budget Reconciliation Act of 1989 (OBRA '89), which is the legislative mandate that health programs supported by MCHB Children with Special Health Care Needs (CSHCN) provide and promote family centered, community-based, coordinated care.

DATA COLLECTION FORM FOR DETAIL SHEET #10

Using a scale of 0-3, please rate the degree to which your grant program has incorporated the following cultural/linguistic competence elements into your policies, guidelines, contracts and training.

Please use the space provided for notes to describe activities related to each element, detail data sources and year of data used to develop score, clarify any reasons for score, and or explain the applicability of elements to program.

| 0 | 1 | 2 | 3 | Element |
|---|---|---|---|---|
| | | | | 1. Strategies for advancing cultural and linguistic competency are integrated into your program's written plan(s) (e.g., grant application, recruiting plan, placement procedures, monitoring and evaluation plan, human resources, formal agreements, etc.). |
| | | | | 2. There are structures, resources, and practices within your program to advance and sustain cultural and linguistic competency. |
| | | | | 3. Cultural and linguistic competence knowledge and skills building are included in training aspects of your program. |
| | | | | 4. Research or program information gathering includes the collection and analysis of data on populations served according to racial, ethnic, and linguistic groupings, where appropriate. |
| | | | | 5. Community and family members from diverse cultural groups are partners in planning your program. |
| | | | | 6. Community and family members from diverse cultural groups are partners in the delivery of your program. |
| | | | | 7. Community and family members from diverse cultural groups are partners in evaluation of your program. |
| | | | | 8. Staff and faculty reflect cultural and linguistic diversity of the significant populations served. |
| | | | | 9. Staff and faculty participate in professional development activities to promote their cultural and linguistic competence. |
| | | | | 10. A process is in place to assess the progress of your program participants in developing cultural and linguistic competence. |

- 0 = Not Met
- 1 = Partially Met
- 2 = Mostly Met
- 3 = Completely Met

Total the numbers in the boxes (possible 0-30 score) _____

NOTES/COMMENTS:

24 PERFORMANCE MEASURE

Goal 4: Improve the Health Infrastructure and Systems of Care
(Assist States and communities to plan and develop comprehensive, integrated health service systems)
Level: State, Community, or Grantee
Category: Infrastructure

The degree to which MCHB-funded initiatives contribute to infrastructure development through core public health assessment, policy development and assurance functions.

GOAL

To develop infrastructure that supports comprehensive and integrated services.

MEASURE

The degree to which MCHB-supported initiatives contribute to the implementation of the 10 MCH Essential Services and Core Public Health Program Functions of assessment, policy development and assurance.

DEFINITION

Attached is a checklist of 10 elements that comprise infrastructure development services for maternal and child health populations. Please score the degree to which each your program contributes to the implementation of each of these elements Each element should be scored 0-2, with a maximum total score of 20 across all elements.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Healthy People Goal 23, Objective 12 (23.12): Increase the proportion of tribes, States, and local health agencies that have implemented a health improvement plan and increase the proportion of local health jurisdictions that have a health improvement plan linked with their State plan.

DATA SOURCE(S) AND ISSUES

Attached data collection form to be completed by grantees based on activities they are directly engaged in or that they contribute to the implementation of by other MCH grantees or programs.

SIGNIFICANCE

Improving the health infrastructure and systems of care is one of the five goals of MCHB. There are five strategies under this goal, all of which are addressed in a number of MCHB initiatives which focus on system-building and infrastructure development. These five strategies follow:

Build analytic capacity for assessment, planning,

and evaluation.

Using the best available evidence, develop and promote guidelines and practices that improve services and systems of care.

Assist States and communities to plan and develop comprehensive, integrated health service systems.

Work with States and communities to assure that services and systems of care reach targeted populations.

Work with States and communities to address selected issues within targeted populations.

The ten elements in this measure are comparable to the 10 Essential Public Health Services outlined in Grason H, Guyer B, 1995. *Public MCH Program Functions Framework: Essential Public Health Services to Promote Maternal and Child Health in America*. Baltimore, MD: The Women's and Children's Health Policy Center, The Johns Hopkins University.

DATA COLLECTION FORM FOR DETAIL SHEET #24

Use the scale below to describe the extent to which your program or initiative has contributed to the implementation of each of the following Public MCH Program core function activities at the local, State, or national level. Please use the space provided for notes to clarify reasons for score

| 0 | 1 | 2 | Element |
|---|---|---|--|
| Assessment Function Activities | | | |
| | | | 1. Assessment and monitoring of maternal and child health status to identify and address problems, including a focus on addressing health disparities [Examples of activities include: developing frameworks, methodologies, and tools for standardized MCH data in public and private sectors; implementing population-specific accountability for MCH components of data systems, and analysis, preparation and reporting on trends of MCH data and health disparities among subgroups.] |
| | | | 2. Diagnosis and investigation health problems and health hazards affecting maternal and child health populations [Examples of activities include conduct of population surveys and reports on risk conditions and behaviors, identification of environmental hazards and preparation of reports on risk conditions and behaviors.] |
| | | | 3. Informing and educating the public and families about MCH issues. |
| Policy Development Function Activities | | | |
| | | | 4. Mobilization of community collaborations and partnerships to identify and solve MCH problems. [Examples of stakeholders to be involved in these partnerships include: policymakers, health care providers, health care insurers and purchasers, families, and other MCH care consumers.] |
| | | | 5. Provision of leadership for priority setting, planning and policy development to support community efforts to assure the health of maternal and child health populations. |
| | | | 6. Promotion and enforcement of legal requirements that protect the health and safety of maternal and child health populations. |
| Assurance Function Activities | | | |
| | | | 7. Linkage of maternal and child health populations to health and other community and family services, and assuring access to comprehensive quality systems of care |
| | | | 8. Assuring the capacity and competency of the public health and personal health workforce to effectively and efficiently address MCH needs. |
| | | | 9. Evaluate the effectiveness, accessibility and quality of direct, enabling and population-based preventive MCH services |
| | | | 10. Research and demonstrations to gain new insights and innovative solutions to MCH-related issues and problems |

0 = Grantee does not provide or contribute to the provision of this activity.
 1 = Grantee sometimes provides or contributes to the provision of this activity.
 2 = Grantee regularly provides or contributes to the provision of this activity
 Total the numbers in the boxes (possible 0–20 score): _____

NOTES/COMMENTS:

26 PERFORMANCE MEASURE

Goal 1: Provide National Leadership for Maternal and Child Health (Strengthen the MCH knowledge base in the MCH community)
Level: Grantee
Category: Training

The extent of training and technical assistance (TA) provided and the degree to which grantees have mechanisms in place to ensure quality in their training and TA activities.

GOAL

To increase the number of MCHB grantees that are using needs assessments, evaluation tools, and applying the results of the evaluation for quality improvement in their training and technical assistance (TA) efforts.

MEASURE

This measure has two components:
A. The number of individuals who were provided training and TA by types of target audiences.
B. The degree to which grantees have put in place key elements to improve the quality of their short- and long-term training and TA activities designed to promote professional and leadership development for the MCH community.

DEFINITION

The training and TA efforts that fall under this measure are short- and medium-term technical assistance and training, not graduate-level and continuing education training provided by MCHB long-term training programs. The target audiences include various populations in the MCH community, including families and other consumers, professionals and providers, State MCH agencies, community-based organizations, and other MCH stakeholders. The eight elements listed in the attached form contribute to promoting quality in the training and TA provided to the MCH community.
Please check the degree to which each of the eight elements have been planned and implemented. The answer scale is 0–3 for each activity or element and 0–24 total across all elements.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Goal 2, focus area: 23) Public Health Infrastructure.

DATA SOURCE(S) AND ISSUES

Attached is a data collection form to be completed by grantees.

SIGNIFICANCE

National Resource Centers, Policy Centers, leadership training institutes and other MCHB

discretionary grantees provide technical assistance and training to various target audiences, including grantees, health care providers, program beneficiaries, and the public as a way of improving skills, increasing the MCH knowledge base, and thus improving capacity to adequately serve the needs of MCH populations and improve their outcomes. To provide these training and TA services most effectively, MCHB has identified performance recommendations, categorized into three categories: 1) activities to promote quality in the content and format of TA and training activities, and prevent duplication of effort ; 2) outreach and promotion to ensure target audiences are aware of the services available to meet their needs, and 3) routine mechanisms to obtain trainee satisfaction and outcomes data and apply what is learned to improve the design and delivery of these services.

DATA COLLECTION FORM FOR DETAIL SHEET #26

PART A

Numbers of individual recipients of training and technical assistance, by categories of target audiences:

(For each individual training or technical assistance activity, individual recipients or attendees should be, counted only once, in one audience category. Trainees who attended more than one training or received more than one type of TA activity should be counted once for each activity they received).

- | | | |
|---|--------------|---|
| 1. Families | ___(yes/no) | ___# of individuals trained/provided TA |
| 2. Other Consumers of Health Services | ___(yes/no) | ___# of individuals trained/provided TA |
| 3. Health Providers/Professionals | ___(yes/no) | ___# of individuals trained/provided TA |
| 4. Education Providers/Professionals | ___(yes/no) | ___# of individuals trained/provided TA |
| 5. State MCH Agency Staff | ___(yes/no) | ___# of individuals trained/provided TA |
| 6. Community-Based/Local Organization Staff | ___(yes/no) | ___# of individuals trained/provided TA |
| 7. Other (specify _____) | ___(yes/no) | ___# of individuals trained/provided TA |
| 8. Unknown | ___(yes/no) | ___# of individuals trained/provided TA |

Total number of individuals trained/provided TA from all audience types _____

PART B

Use the scale described below to indicate the degree to which your grant has incorporated each of the design, evaluation, and continuous quality improvement activities into your training and TA work. Please use the space provided for notes to describe activities related to each element and clarify reasons for the score.

| 0 | 1 | 2 | 3 | Element |
|--|---|---|---|---|
| Mechanisms in Place to Ensure Quality in Design of Training and TA Activities | | | | |
| | | | | <p>1. Build on Existing Information Resources and Expertise, and Ensure Up-to-Date Content. As part of the development of training and technical assistance services, the grantee conducts activities (such as reviewing existing bibliographies, information resources, or other materials) to ensure that the information provided in newly developed training curricula and technical assistance materials and services is up to date with standard practice; based on research, evidence, and best practice-based literature or materials in the MCH field; and is aligned with local, State, and/or Federal initiatives. Grantee uses these mechanisms to ensure that information resource content does not duplicate existing training and technical assistance available to the same audience. Also include in the design and development expert review panels (experts may include target audience members).</p> |
| | | | | <p>2. Link to Other MCH Grantees Training and TA Activities. The training and TA provided by this grantee is linked to the content and timing of training offered by other MCH grantees (e.g., Family-to-Family Health Information Centers, other national resource and training centers, State and local CSHCN/MCH programs).</p> |
| | | | | <p>3. Obtain Input from the Target Audience to Ensure Relevancy</p> |

| 0 | 1 | 2 | 3 | Element |
|--|---|---|---|---|
| | | | | to their Needs. The grantee routinely obtains input from the audience targeted for each training or TA activity before finalizing the curriculum or materials. This could include a determination of whether the content and language of the materials are relevant to the audience’s current needs and are understandable. Training and TA should also be relevant with respect to timeliness, ensuring that they reach trainees when needed. |
| | | | | 4. Ensure Cultural and Linguistic Appropriateness. The grantee employs mechanisms to ensure that training and TA materials, methods, and content are culturally and linguistically appropriate. |
| Mechanisms in Place to Promote Grantee’s Training and Technical Assistance Services | | | | |
| | | | | 5. Conduct Outreach and Promotion to Ensure Target Audience is Aware of TA and Training Services. The grantee routinely uses mechanisms to reach out to MCHB grantees and other target audiences such as provider or family organizations, consumers of MCH services, and the public, to make sure that target audiences know the services are available. (Examples of outreach methods include promotion of services through list serves, exhibits at meetings, and targeted outreach to representatives of individual organizations or MCHB grantees.) |
| Mechanisms in Place to Evaluate Training and TA Activities and Use the Data for Quality Improvement | | | | |
| | | | | 6. Collect Satisfaction Data. The grantee routinely uses mechanisms, such as evaluation forms, to collect satisfaction data from recipients of training or TA. |
| | | | | 7. Collect Outcome Data. The grantee routinely collects data to assess whether recipients have increased their knowledge, leadership skills, and ability to apply new knowledge and skills to their family, health care practice, or other MCH program situation. |
| | | | | 8. Use Feedback for Quality Improvement. The degree to which the grantee has used the results of assessments or other feedback mechanisms to improve the content, reach and effectiveness of the training or TA activities. |

0=Not Met
1=Partially Met
2=Mostly Met
3=Completely Met

Total the numbers in the boxes (maximum possible 0–24): _____

NOTES/COMMENTS:

27 PERFORMANCE MEASURE

Goal 4: Improve the Health Infrastructure and Systems of Care by Improving MCH Knowledge and Available Resources

Level: Grantee

Category: Infrastructure

The degree to which grantees have mechanisms in place to ensure quality in the design, development, and dissemination of new information resources that they produce each year.

GOAL

To improve the dissemination of new knowledge to the MCH field by increasing the quality of informational resources produced, including articles, chapters, books, and other materials produced by grantees, and by addressing the quality in design and development. This includes consumer education materials, conference presentations, and electronically available materials.

MEASURE

The degree to which grantees have mechanisms in place to ensure quality in the design, development, and dissemination of new informational resources they produce each year.

DEFINITION

Publications are articles, books, or chapters published during the year being reported. Products include electronic Web-based resources, video training tapes, CD ROMs, DVD, materials created for consumers (parents, children, and community agencies). Products and publications also include outreach and marketing materials (such as presentations, alerts, and HRSA clearinghouse materials).

Details on these publications and products are reported on a data collection form. These products are summed by category and the total number of all publications and products are reported on a PM tracking form for a reporting year.

This measure can be applicable to any MCHB grantee.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Goal 1: Improve access to comprehensive, high-quality health care services. Specific objective: 1.3.

Related to Goal 7 – Educational and community-based programs: Increase the quality, availability and effectiveness of educational and community-based programs designed to prevent disease and improve health and quality of life. Specific objectives: 7.7 through 7.12.

Related Goal 11 – Use communication strategically to improve health. Specific objective: 11.3.

Related to Goal 23 – Public Health Infrastructure: Ensure that Federal, tribal, State, and local health

agencies have the infrastructure to provide essential public health services effectively. Specific objective: 23.2.

DATA SOURCE(S) AND ISSUES

Data will be collected by grantees throughout the year and reported in their annual reports and via this measure's data collection form.

SIGNIFICANCE

Advancing the field of MCH based on evidence-based, field-tested quality products. Collection of the types of and dissemination of MCH products and publications is crucial for advancing the field. This PM addresses the production and quality of new informational resources created by grantees for families, professionals, other providers, and the public.

DATA COLLECTION FORM FOR DETAIL SHEET #27

Using the 0–3 scale below indicate the degree to which your grant has incorporated each of the design, dissemination, and continuous quality improvement activities into MCH information resources that you have developed within the past year. Please use the space provided for notes to describe activities related to each element and clarify any reasons for the score

| 0 | 1 | 2 | 3 | Element |
|--|---|---|---|---|
| Mechanisms in Place to Ensure Quality in Design of Informational Resources | | | | |
| | | | | <p>1. Obtain input from the target audience or other experts to ensure relevance. The grantee conducts activities to ensure the information resource is relevant to the target audience with respect to knowledge, issues, and best practices in the MCH field. [Example: Obtain target audience, user, or expert input in the design of informational resources, the testing or piloting of products with the potential users/audience, and the use of expert reviews of new products.]</p> |
| | | | | <p>2. Obtain input from the target audience or other experts to ensure cultural and linguistic appropriateness. The grantee specifically employs mechanisms to ensure that resources are culturally and linguistically appropriate to meet the needs and level of the target audience(s).</p> |
| | | | | <p>3. Build on Existing Information Resources and Expertise, and Ensure Up-to-Date Content. As part of the development of information resources, the grantee conducts activities (such as reviewing existing bibliographies, information resources, or other materials) to ensure that the information provided in newly developed information resources is up to date with standard practice; based on research-, evidence-, and best practice-based literature or materials in the MCH field; and is aligned with local, State, and/or Federal initiatives. Grantee uses these mechanisms to ensure that information resource content does not duplicate existing resources available to the same audience. Also include in the design and development expert review panels (experts may include target audience members).</p> |
| Mechanisms in Place to Track Dissemination and Use of Resources or Products | | | | |
| | | | | <p>4. The grantee has a system to track, monitor, and analyze the dissemination and reach of products. The grantee implements a mechanism for tracking and documenting dissemination of products, and uses this information to ensure the target audience(s) is reached. Grantees with a Web site should include mechanisms for tracking newly created resources disseminated through their Web sites and are encouraged to detail Web-related dissemination mechanisms and the use of Web-based products in the Notes section below. Grantee ensures that format is accessible to diverse audiences and conforms to ADA guidelines and to Section 508 of the Rehabilitation Act.</p> |
| | | | | <p>5. The grantee has a system in place to track, monitor, and analyze the use of products. The grantee routinely collects data from the recipients of its products and resources to assess their satisfaction with products, and whether products are useful, share new and relevant information, and enhance MCH knowledge. [An example of data collection is assessments.]</p> |

| 0 | 1 | 2 | 3 | Element |
|---|---|---|---|---|
| Mechanisms in Place to Promote Grantee's Information Resources | | | | |
| | | | | <p>6. Conduct Culturally Appropriate Outreach and Promotion to Ensure Target Audience is Aware of Information Resources The grantee routinely uses mechanisms to reach out to MCHB grantees and other target audiences such as provider or family organizations, consumers of MCH services, and the public, to make sure that target audiences know the resources are available. [Examples of outreach methods include promotion of services through list serves, exhibits at meetings, and targeted outreach to representatives of individual organizations or MCHB grantees.]</p> |
| Use of Evaluation Data for Quality Improvement | | | | |
| | | | | <p>7. Use of Feedback for Quality Improvement. The degree to which the grantee has used the results of satisfaction and other feedback mechanisms to improve the content, reach, and effectiveness of their products/information resources.</p> |

0=Not Met
 1=Partially Met
 2=Mostly Met
 3=Completely Met

Total the numbers in the boxes (possible 0–21 score): _____

NOTES/COMMENTS:

33 PERFORMANCE MEASURE

The degree to which MCHB-funded initiatives work to promote sustainability of their programs or initiatives beyond the life of MCHB funding.

Goal 4: Improve the Health Infrastructure and Systems of Care (Assist States and communities to plan and develop comprehensive, integrated health service systems)

Level: Grantee

Category: Infrastructure

GOAL

To develop infrastructure that supports comprehensive and integrated systems of care for maternal and child health at the local and/or state level.

MEASURE

The degree to which MCHB grantees are planning and implementing strategies to sustain their programs once initial MCHB funding ends.

DEFINITION

Attached is a checklist of nine actions or strategies that build toward program sustainability. Please check the degree to which each of the elements is being planned or carried out by your program, using the three-point scale. The maximum total score for this measure would be 27 across all elements.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Healthy People Goal 23, Objective 12 (23.12): Increase the proportion of Tribes, States, and local health agencies that have implemented a health improvement plan and increase the proportion of local health jurisdictions that have a health improvement plan linked with their State plan.

DATA SOURCE(S) AND ISSUES

Attached is a data collection form to be completed by grantees. Since these actions and their outcomes are necessarily progressive over time from the beginning to the end of a program funding period, grantees' ratings on each element are expected to begin lower in the first year of grant award and increase over time.

SIGNIFICANCE

In recognition of the increasing call for recipients of public funds to sustain their programs after initial funding ends, MCHB encourages grantees to work toward sustainability throughout their grant periods. A number of different terms and explanations have been used as operational components of sustainability. These components

fall into four major categories, each emphasizing a distinct focal point as being at the heart of the sustainability process: (1) adherence to program principles and objectives, (2) organizational integration, (3) maintenance of health benefits, and (4) State or community capacity building. Specific recommended actions that can help grantees build toward each of these four sustainability components are included as the data elements for this PM.

DATA COLLECTION FORM FOR DETAIL SHEET #33

Use the scale below to rate the degree to which your program has taken the following actions to promote sustainability of your program or initiative. Since these actions and their outcomes are necessarily progressive over the funding period, the ratings are expected to begin lower and progress over the grant period.

Please use the space provided for notes to clarify reasons for score.

| 0 | 1 | 2 | 3 | Element |
|---|---|---|---|---|
| | | | | 1. A written sustainability plan is in place within two years of the MCHB grant award, with goals, objectives, action steps, and timelines to monitor plan progress. |
| | | | | 2. Staff and leaders in the organization engage and build partnerships with consumers, and other key stakeholders in the community, in the early project planning, and in sustainability planning and implementation processes. |
| | | | | 3. There is support for the MCHB-funded program or initiative within the parent agency or organization, including from individuals with planning and decision making authority. |
| | | | | 4. There is an advisory group or a formal board that includes family, community and state partners, and other stakeholders who can leverage resources or otherwise help to sustain the successful aspects of the program or initiative. |
| | | | | 5. The program's successes and identification of needs are communicated within and outside the organization among partners and the public, using various internal communication, outreach and marketing strategies. |
| | | | | 6. The grantee identified, actively sought, and obtained other funding sources and in-kind resources to sustain the program or initiative. |
| | | | | 7. Policies and procedures developed for the successful aspects of the program or initiative are incorporated into the parent or another organization's system of programs and services. |
| | | | | 8. The responsibilities for carrying out key successful aspects of the program or initiative have begun to be transferred to permanent staff positions in other ongoing programs or organizations. |
| | | | | 9. The grantee has secured financial or in-kind support from within the parent organization or external organizations to sustain the successful aspects of the MCHB-funded program or initiative. |

- 0 = Not Met
- 1 = Partially Met
- 2 = Mostly Met
- 3 = Completely Met

Total the numbers in the boxes (possible 0–27 score): _____

NOTES/COMMENTS:

37 PERFORMANCE MEASURE

**Goal 4: Improve the Health Infrastructure and Systems of Care
(Work with States and communities to assure that services and systems of care reach targeted populations)
Level: Grantee
Category: CSHN/Youth**

The degree to which grantees have worked to increase the percentage of youth who have received services necessary to transition to all aspects of adult life, including adult health care, work, and independence.

GOAL

To assure that youth with and without special health care needs, including those transitioning from foster care, receive the services necessary to transition to adult health care, work, and independence.

MEASURE

The degree to which grantees have assisted in ensuring that youth receive the services necessary to transition to adult health care, work, and independence.

DEFINITION

Attached is a checklist of 13 elements that demonstrate how a grantee has assisted ensuring appropriate transition for adolescents. Please check the degree to which the elements have been implemented.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Objective 16.23: Increase the proportion of States and jurisdictions that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239.

DATA SOURCE(S) AND ISSUES

Attached data collection form to be completed by grantees.
The data collection form represents 10 elements that demonstrate comprehensive transition services for youth.

SIGNIFICANCE

The transition of youth to adulthood has become a priority issue nationwide as evidenced by the President's "New Freedom Initiative: Delivering on the Promise"(March, 2002). Health and health care are cited as two of the major barriers to making successful transitions. Currently SPRANS supported health and related transition services are available in only a few States. No other Federal agency is addressing these issues. Successful preparation for the adult work force is important for all youth and is based on healthy developmental transitions between childhood and adolescence, and between adolescence and adulthood.

DATA COLLECTION FORM FOR DETAIL SHEET #37

Using the scale below, please indicate for each element the degree to which you have assisted in the provision or assurance of comprehensive Healthy and Ready to Work services to adolescents and young adults. Please use the space provided for notes to describe activities related to each element and clarify reasons for score.

| 0 | 1 | 2 | 3 | Elements |
|---|---|---|---|--|
| Outcome #1: Screening | | | | |
| | | | | 1. Screening mechanisms include developmental and transition skills as a regular part of health services for youth. |
| Outcome #2: Family Partnerships | | | | |
| | | | | 2. The grantee has created a youth advisory council and mentors youth leaders as they serve on this council. |
| | | | | 3. The grantee assures that youth leaders serve on state and local advisory boards and planning committees. |
| Outcome #3: Medical Home | | | | |
| | | | | 4. The grantee has identified medical homes for young people which assume responsibility for health care, care coordination, and transition to an adult health care provider. |
| | | | | 5. Pediatric and adult medical care providers are trained to offer information and support in caring for young people with and without complex condition. |
| Outcome #4: Health Insurance | | | | |
| | | | | 6. Primers on maintaining health insurance after age 18 are developed and distributed to a variety of community settings, including schools, providers, parent resource groups, and others. |
| | | | | 7. A matrix of health care insurance options (public and private) is developed. |
| | | | | 8. The grantee is working with a variety of partners to promote youth-friendly insurance policies, including the extension of dependent coverage to age 26. |
| Outcome #4: Community-Based Services | | | | |
| | | | | 9. Information on medical aspects of pediatric-onset conditions and community resources for youth is provided in a variety of media, including conferences, newsletters, brochures, and Web sites. |
| | | | | 10. The focus of services is on development of self-care abilities, transportation, housing, access to quality health care and insurance, personal care assistants and job training and supports, independent living training, and assistive technology that is affordable and portable. |
| | | | | 11. The grantee has worked with providers of adult care to provide education in the needs of adolescents as they transition to adulthood, including the need to discuss the shift to adult providers. |
| Outcome #6: Transition | | | | |
| | | | | 12. The grantee has worked to improve coordinated transition from pediatric to adult primary care providers for adolescents in the State, including the |

| 0 | 1 | 2 | 3 | Elements |
|---|---|---|---|---|
| | | | | provision of health representation at transition planning meetings aimed at education, employment, or independence. |
| | | | | 13. The grantee has worked to provide adolescents with self-advocacy or self-determination training to help them to take responsibility for their own health and health care. |

0 = Not Met
 1 = Partially Met
 2 = Mostly Met
 3 = Completely Met

Total the numbers in the boxes (possible 0-39 score)_____

NOTES/COMMENTS:

41 PERFORMANCE MEASURE

**Goal 3: Ensure Quality of Care
(Develop and promote health services and
systems designed to improve quality of care)
Level: National
Category: Medical Home**

The degree to which grantees have assisted in developing, supporting, and promoting medical homes for MCH populations.

GOAL

To increase the prevalence of medical homes within the systems that serve MCH populations.

MEASURE

The degree to which grantees have assisted in developing and supporting systems of care for MCH populations that promote the medical home.

DEFINITION

Attached is a set of five categories with a total of 24 elements that contribute to a family/patient-centered, accessible, comprehensive, continuous, and compassionate system of care for MCH populations. Please use the space provided for notes to describe activities related to each element and clarify reasons for score.

HEALTHY PEOPLE 2010 OBJECTIVE

Related to Objective 16.22 (Developmental): Increase the proportion of CSCHN who have access to a medical home.

DATA SOURCE(S) AND ISSUES

Attached is a data collection form to be completed by grantees. The data collection form presents a range of activities that contribute to the development of medical homes for MCH populations.

SIGNIFICANCE

Providing primary care to children in a “medical home” is the standard of practice. Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventive care and immunizations, less likely to be hospitalized for preventable conditions, and more likely to be diagnosed early for chronic or disabling conditions. Data collected for this measure would help to ensure that children have access to a medical home and help to document the performance of several programs, including EPSDT, immunization, and IDEA in reaching that goal.

DATA COLLECTION FORM FOR DETAIL SHEET #41

Using the scale below, indicate the degree to which your grant has assisted in the development and implementation of medical homes for MCH populations. Please use the space below to indicate the year the score is reported for and clarify reasons for the score.

Indicate population: pregnant and postpartum women, infants, children, children with special health care needs, adolescents

(While this is a single performance measure, for analytic purposes each of the categories will be scored as an independent measure. Grantees may identify specific categories as not applicable to their grant program by selecting a score of 0 for every item within the category.)

| 0 | 1 | 2 | 3 | Element |
|---|---|---|---|---|
| Category A: Establishing and Supporting Medical Home Practice Sites | | | | |
| | | | | 1. The grantee has conducted needs and capacity assessments to assess the adequacy of the supply of medical homes in their community, state, or region. |
| | | | | 2. The grantee has recruited health care providers to become the medical homes. |
| | | | | 3. The grantee has developed or adapted training curricula for primary care providers in the medical home concept. |
| | | | | 4. The grantee has provided training to health care providers in the definition and implementation of the medical home and evaluated its effectiveness. |
| | | | | 5. The grantee has assisted practice sites in implementing health information technologies in support of the medical home. |
| | | | | 6. The grantee has developed/implemented tools for the monitoring and improvement of quality within medical homes. |
| | | | | 7. The grantee has disseminated validated tools such as the Medical Home Index to practice sites and trained providers in their use. |
| | | | | 8. The grantee has developed/implemented quality improvement activities to support medical home implementation. |
| Category A Subtotal (possible 0-24): | | | | |
| Category B: Developing and Disseminating Information and Policy Development Tools: The grantee has developed tools for the implementation of the medical home and promoted the medical home through policy development | | | | |
| | | | | 9. Referral resource guides |
| | | | | 10. Coordination protocols |
| | | | | 11. Screening tools |

| 0 | 1 | 2 | 3 | Element |
|---|---|---|---|---|
| | | | | 12. Web sites |
| | | | | 13. The grantee has developed and promoted policies, including those concerning data-sharing, on the State or local level to support the medical home |
| | | | | 14. The grantee has provided information to policymakers in issues related to the medical home |
| Category B Subtotal (possible 0-18): | | | | |
| Category C: Public Education and Information Sharing: The grantee has implemented activities to inform the public about the medical home and its features and benefits | | | | |
| | | | | 15. The grantee has developed Web sites and/or other mechanisms to disseminate medical home information to the public. |
| | | | | 16. The grantee has provided social service agencies, families and other appropriate community-based organizations with lists of medical home sites. |
| | | | | 17. The grantee has engaged in public education campaigns about the medical home. |
| Category C Subtotal (possible 0-9): | | | | |
| Category D: Partnership-Building Activities | | | | |
| | | | | 18. The grantee has established a multidisciplinary advisory group, including families and consumers representative of the populations served, to oversee medical home activities |
| | | | | 19. The grantee has coordinated and/or facilitated communication among stakeholders serving MCH populations (e.g., WIC, domestic violence shelters, local public health departments, rape crisis centers, and ethnic/culturally-based community health organizations) |
| | | | | 20. The grantee has worked with the State Medicaid agency and other public and private sector purchasers on financing of the medical home. |
| | | | | 21. The grantee has worked with health care providers and social service agencies to implement integrated data systems. |
| Category D Subtotal (possible 0-12): | | | | |
| Category E: Mentoring Other States and Communities | | | | |
| | | | | 22. The degree to which the grantee has shared medical home tools with other communities and States. |
| | | | | 23. The degree to which the grantee has presented its experience establishing and supporting medical homes to officials of other communities, family champions, and/or States at national meetings |

| 0 | 1 | 2 | 3 | Element |
|-------------------------------------|---|---|---|--|
| | | | | 24. The degree to which the grantee has provided direct consultation to other States on policy or program development for medical home initiatives |
| Category E Subtotal (possible 0-9): | | | | |

- 0 = Not Met
- 1 = Partially Met
- 2 = Mostly Met
- 3 = Completely Met

Total the numbers in the boxes (possible 0-72 score)_____

NOTES/COMMENTS:

Products, Publications and Submissions Data Collection Form

Part 1

Instructions: Please list the number of products, publications and submissions addressing maternal and child health that have been published or produced by your staff during the reporting period (counting the original completed product or publication developed, not each time it is disseminated or presented). Products and Publications include the following types:

| Type | Number |
|--|--------|
| Peer-reviewed publications in scholarly journals – published (including peer-reviewed journal commentaries or supplements) | |
| Peer-reviewed publications in scholarly journals – submitted | |
| Books | |
| Book chapters | |
| Reports and monographs (including policy briefs and best practices reports) | |
| Conference presentations and posters presented | |
| Web-based products (Blogs, podcasts, Web-based video clips, wikis, RSS feeds, news aggregators, social networking sites) | |
| Electronic products (CD-ROMs, DVDs, audio or videotapes) | |
| Press communications (TV/Radio interviews, newspaper interviews, public service announcements, and editorial articles) | |
| Newsletters (electronic or print) | |
| Pamphlets, brochures, or fact sheets | |
| Academic course development | |
| Distance learning modules | |
| Doctoral dissertations/Master’s theses | |
| Other | |

Part 2

Instructions: For each product, publication and submission listed in Part 1, complete all elements marked with an “*”

Data collection form: Peer-reviewed publications in scholarly journals – published

*Title: _____
*Author(s): _____
*Publication: _____
*Volume: _____ *Number: _____ Supplement: _____ *Year: _____ *Page(s): _____
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
*To obtain copies (URL): _____
Key Words (No more than 5): _____
Notes: _____

Data collection form: Peer-reviewed publications in scholarly journals – submitted

*Title: _____
*Author(s): _____
*Publication: _____
*Year Submitted: _____
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
Key Words (No more than 5): _____
Notes: _____

Data collection form: Books

*Title: _____
*Author(s): _____
*Publisher: _____
*Year Published: _____
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
Key Words (No more than 5): _____
Notes: _____

Data collection form for: Book chapters

Note: If multiple chapters are developed for the same book, list them separately.

*Chapter Title: _____
*Chapter Author(s): _____
*Book Title: _____
*Book Author(s): _____
*Publisher: _____
*Year Published: _____
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
Key Words (no more than 5): _____
Notes: _____

Data collection form: Reports and monographs

*Title: _____
*Author(s)/Organization(s): _____
*Year Published: _____
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
*To obtain copies (URL or email): _____
Key Words (no more than 5): _____
Notes: _____

Data collection form: Conference presentations and posters presented

(This section is not required for MCHB Training grantees.)

*Title: _____
*Author(s)/Organization(s): _____
*Meeting/Conference Name: _____
*Year Presented: _____
*Type: Presentation Poster
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
*To obtain copies (URL or email): _____
Key Words (no more than 5): _____
Notes: _____

Data collection form: Web-based products

*Product: _____

*Year: _____

- *Type: Blogs Podcasts Web-based video clips
 Wikis RSS feeds News aggregators
 Social networking sites Other (Specify)

*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___

*To obtain copies (URL): _____

Key Words (no more than 5): _____

Notes: _____

Data collection form: Electronic Products

*Title: _____

*Author(s)/Organization(s): _____

*Year: _____

- *Type: CD-ROMs DVDs Audio tapes
 Videotapes Other (Specify)

*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___

*To obtain copies (URL or email): _____

Key Words (no more than 5): _____

Notes: _____

Data collection form: Press Communications

*Title: _____

*Author(s)/Organization(s): _____

*Year: _____

- *Type: TV interview Radio interview Newspaper interview
 Public service announcement Editorial article Other (Specify)

*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___

*To obtain copies (URL or email): _____

Key Words (no more than 5): _____

Notes: _____

Data collection form: Newsletters

*Title: _____
*Author(s)/Organization(s): _____
*Year: _____
*Type: Electronic Print Both
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
*To obtain copies (URL or email): _____
*Frequency of distribution: Weekly Monthly Quarterly Annually Other (Specify)
Number of subscribers: _____
Key Words (no more than 5): _____
Notes: _____

Data collection form: Pamphlets, brochures or fact sheets

*Title: _____
*Author(s)/Organization(s): _____
*Year: _____
*Type: Pamphlet Brochure Fact Sheet
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
*To obtain copies (URL or email): _____
Key Words (no more than 5): _____
Notes: _____

Data collection form: Academic course development

*Title: _____
*Author(s)/Organization(s): _____
*Year: _____
*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___
*To obtain copies (URL or email): _____
Key Words (no more than 5): _____
Notes: _____

Data collection form: Distance learning modules

*Title: _____

*Author(s)/Organization(s): _____

*Year: _____

*Media Type: Blogs Podcasts Web-based video clips
 Wikis RSS feeds News aggregators
 Social networking sites CD-ROMs DVDs
 Audio tapes Videotapes Other (Specify)

*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___

*To obtain copies (URL or email): _____

Key Words (no more than 5): _____

Notes: _____

Data collection form: Doctoral dissertations/Master's theses

*Title: _____

*Author: _____

*Year Completed: _____

*Type: Doctoral dissertation Master's thesis

*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___

*To obtain copies (URL or email): _____

Key Words (no more than 5): _____

Notes: _____

Other

(Note, up to 3 may be entered)

*Title: _____

*Author(s)/Organization(s): _____

*Year: _____

*Describe product, publication or submission: _____

*Target Audience: Consumers/Families ___ Professionals ___ Policymakers ___ Students ___

*To obtain copies (URL or email): _____

Key Words (no more than 5): _____

Notes: _____