

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

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

***National Genetics Education and Family Support Center***

**Announcement Type:** New  
**Funding Opportunity Number:** HRSA-17-083

**Catalog of Federal Domestic Assistance (CFDA) No. 93.110**

**FUNDING OPPORTUNITY ANNOUNCEMENT**

Fiscal Year 2017

Letter of Intent Due Date: November 1, 2016

**Application Due Date: December 13, 2016**

*Ensure SAM.gov and Grants.gov registrations and passwords are current immediately!  
Deadline extensions are not granted for lack of registration.  
Registration in all systems, including SAM.gov and Grants.gov,  
may take up to one month to complete.*

**Issuance Date: September 27, 2016**

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Authority: SPRANS, Title V, § 501(a)(2) of the Social Security Act, as amended (42 U.S.C. 701(a)(2)).

## EXECUTIVE SUMMARY

The Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), is accepting applications for fiscal year FY 2017 National Genetics Education and Family Support Center. The purpose of this program is to:

- 1) improve family engagement for individuals and families who have, or at-risk of having, a genetic condition;
- 2) provide support for such individuals and families;
- 3) provide education and resources on genetic conditions; and
- 4) link individuals and families to services, especially those in underserved areas.

Funding Opportunity Title:	National Genetics Education and Family Support Center
Funding Opportunity Number:	HRSA-17-083
Due Date for Applications:	December 13, 2016
Anticipated Total Annual Available Funding:	\$400,000
Estimated Number and Type of Award(s):	Up to one (1) cooperative agreement
Estimated Award Amount:	Up to \$400,000 per year
Cost Sharing/Match Required:	No
Project Period:	June 1, 2017 through May 31, 2020 (three (3) years)
Eligible Applicants:	Per 42 CFR § 51a.3(a), any public or private entity, including an Indian tribe or tribal organization (as those terms are defined at 25 U.S.C. 450b) is eligible to apply. Faith-based and community-based organizations are eligible to apply. [See <a href="#">Section III-1</a> of this funding opportunity announcement (FOA) for complete eligibility information.]

### **Application Guide**

You (the applicant organization/agency) are responsible for reading and complying with the instructions included in HRSA's *SF-424 Application Guide*, available online at <http://www.hrsa.gov/grants/apply/applicationguide/sf424guide.pdf>, except where instructed in this FOA to do otherwise. A short video explaining the *Application Guide* is available at <http://www.hrsa.gov/grants/apply/applicationguide/>.

### **Technical Assistance**

MCHB will host a pre-submission technical assistance webinar for all prospective applicants on October 27, 2016 at 3:00 – 4:00 pm Eastern Time. Call details are as follows:

Time: 3:00 - 4:00 pm ET

Dial-in: 1-866-723-0810; Participants Passcode 31341820

Web Link: <https://hrsa.connectsolutions.com/nesc>

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# **I. Program Funding Opportunity Description**

## **1. Purpose**

This announcement solicits applications for the National Genetics Education and Family Support Center to: 1) improve family engagement for individuals and families who have, or at-risk of having, a genetic condition; 2) provide support for such individuals and families; 3) provide education and resources on genetic conditions; and 4) link individuals and families to services, especially those in underserved areas.

## **Program Goals**

The goal of the National Genetics Education and Family Support Center (Family Center) is to: ensure that all individuals who have, or are at-risk of having, a genetic condition and their families, especially those medically underserved and/or living in geographically underserved areas<sup>1</sup>, have access to genetic services, are engaged in their own care, and have opportunities to engage in a meaningful way in national, regional, and local genetic services systems.

The Family Center will serve as a national resource for patient-centered information that is culturally sensitive to diverse populations; collaborates with the Regional Genetics Networks (RGN), HRSA-17-082, and the National Coordinating Center (NCC) for the Regional Genetics Networks (RGN), HRSA-17-084, in reaching underserved populations targeted by the RGNs; and develops family leaders who can participate in national, regional, and local genetic service systems.

## **Program Objectives**

- 1) By 2020, increase by ten (10) percent from baseline the number of families/parents/caregivers trained and serving in meaningful roles on national, regional, and local genetic service systems.
- 2) By 2020, increase by twenty (20) percent from baseline the number of families/parents/caregivers trained that report increased knowledge, skill, ability and self-efficacy to serve as leaders on genetic service systems-level teams.
- 3) By 2020, increase by twenty (20) percent from baseline the number of individuals using a national online resource of genetic information and links to services and resources.

## Program Requirements

To achieve the goals of the program, the Family Center must:

- 1) Support a national web-based resource to link all patients to genetic information and services, with an emphasis on underserved populations;
- 2) Use needs assessment data to develop and disseminate a portfolio of educational information about genetics and genetic conditions that assist families in understanding genetics and their conditions;
- 3) Develop and disseminate a portfolio of leadership and family engagement materials to support family partnership, engagement, and leadership in the genetics care delivery system;
- 4) Collaborate with the RGNs and NCC to reach underserved populations by:
  - a. Providing technical assistance and training on patient outreach and engagement;
  - b. Developing culturally and linguistically appropriate shared outreach materials; and
  - c. Partnering with cultural and community-based organizations to enhance outreach to underserved populations selected by the RGNs.
- 6) Assist RGNs and the NCC to recruit new family leaders for workgroups and advisory groups.
- 7) Partner with and provide technical assistance on genetics to other MCHB family leadership programs including, but not limited to, the Family-to-Family Health Information Centers, the National Professional/Family Partnership Centers, and the Family Leadership in Language and Learning Center.

Baseline data will be collected by the end of Year 1, May 31, 2018:

- 1) Number of families/parents/caregivers trained and serving in meaningful roles on national, regional, and local genetic service systems.
- 2) Number of families/parents/caregivers trained that report increased knowledge, skill, ability and self-efficacy to serve as leaders on genetic service systems-level teams.
- 3) Number of individuals using a national online resource of genetic information and links to services and resources.
- 4) Implementation and use of an online resource of materials and tools for all patients/families with genetic conditions.
  - a. Number of educational materials, training tools, and other resources
  - b. Numbers and types of visitors to online resources.
  - c. Framework and tools assessed for cultural appropriateness.
- 5) Number and type of technical assistance activities to RGNs, the NCC, other family leadership program.
- 6) Number of partnerships with community organizations and other family leadership programs.
- 7) Number of families recruited for representation on advisory groups or workgroups.
- 8) Number of individuals representing underserved populations receiving services.

## 2. Background

The program is authorized by SPRANS, Title V, § 501(a)(2) of the Social Security Act, as amended (42 U.S.C. 701(a)(2)), which requires HRSA to provide “for genetic disease testing, counseling, and information development and dissemination programs.”

Current evidence shows that patient-centered care includes communication and coordination of care at all levels of the health care system, including at the direct care, organizational design and governance, and policymaking levels.<sup>1</sup> For children and youth with special health care needs (CYSHCN), family engagement can result in improved patient-centered care and health outcomes (e.g., physical and emotional function, transition from pediatric to adult health care systems, cost, etc.).<sup>2</sup> However, recent survey data also indicate that 30 percent (approximately 3.3 million) of U.S. CYSHCN families do not feel as though they are partners in their child’s care.<sup>3</sup> There are also notable disparities in how racial and ethnic minority families with CYSHCN experience family engagement.<sup>4</sup>

In addition to these difficulties, CYSHCN with genetic conditions experience particular challenges in getting access to appropriate services, as many providers are unfamiliar with genetic conditions. In a 2015 survey of 1,355 participants with genetic conditions<sup>5</sup>, nearly one-third reported that it took more than five years from symptoms appearing to receive a diagnosis; a significant delay in identifying, managing and treating the condition. Findings also show that 50 percent of respondents reported that the first place they look for information on their condition is on the internet. Twenty-nine percent look for social/emotional support through support or advocacy organizations, and 24 percent from a fellow parent of an individual with the condition. Moreover, participants also reported substantive barriers in accessing social and emotional support services, specialist visits, and therapies. Approximately 42 percent said that they never or rarely received social/emotional support from their healthcare providers. Genetic conditions can also be very complex, requiring care from multiple providers. In a 2013 survey of 1,895 individuals with genetic conditions, the majority of participants received care from multiple providers; yet only one in five had someone that helped arrange or coordinate their care.<sup>7</sup>

The National Genetics Education and Family Support Center will build off existing resources and serve as a new national resource center to help families engage in their care. The new Family Center will fill the gaps identified above by individuals and their families with genetic conditions, help ensure that families know how to access genetic services, and support the training of family leaders for state, regional and national leadership and decision-making roles. The Family Center will work collaboratively with

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<sup>1</sup> IOM (Institute of Medicine). 2011. *Patients charting the course: Citizen engagement and the learning health system: Workshop summary*. Washington, DC: The National Academies Press.

<sup>2</sup> Ngui (2006); Scal (2005); Baruffi (2005); Smaldone (2005); Young (2005); Fiks et al. (2012); Fiks et al. (2010); Janssen et al. (2007); Wilson et al. (2010); Smalley et al. (2014).

<sup>3</sup> Smalley et al. (2014).

<sup>4</sup> 2009-2010 National Survey of Children with Special Health Care Needs data.

<sup>5</sup> Unpublished survey data.

<sup>7</sup> Genetic Alliance Survey, unpublished data (2015).

the Regional Genetic Networks (RGNs) and National Coordinating Center (NCC) specifically to support families in underserved populations.

## **Maternal and Child Health Bureau**

MCHB is a component of HRSA within the U.S. Department of Health and Human Services (HHS). Since its inception, maternal and child health (MCH) services grants have provided a foundation for ensuring the health of our nation's mothers and children. The mission of MCHB is to provide national leadership in partnership with key stakeholders, to reduce disparities, assure availability of quality care, and strengthen the nation's MCH/public health infrastructure in order to improve the physical and mental health, safety and well-being of the MCH population.

## **The Division of Services for Children with Special Health Needs**

With the Omnibus Budget Reconciliation Act of 1989, Public Law 101-239 amended Title V of the Social Security Act to extend the authority and responsibility of MCHB to address the core elements of community-based systems of services for CYSHCN and their families. With this amendment, State Title V programs under the MCH Services Block Grant program were given the responsibility to provide and promote family-centered, community-based, coordinated care for CYSHCN and facilitate the development of community-based systems of services for such children and their families. CYSHCN are defined as "those children and youth who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." According to the National Survey of Children with Special Health Care Needs (2009/2010),<sup>8</sup> 15.1 percent of children under 18 years of age in the United States, or approximately 11.2 million children, are estimated to have special health care needs. Overall, 23 percent of U.S. households with children have at least one child with special health care needs.

Through grant initiatives, DSCSHN works to achieve the following six critical systems outcomes:

- 1) Family/professional partnership at all levels of decision making.
- 2) Access to coordinated ongoing comprehensive care within a medical home.
- 3) Access to adequate private and/or public insurance and financing to pay for needed services.
- 4) Early and continuous screening for special health needs.
- 5) Organization of community services for easy use.
- 6) Youth transition to adult health care, work, and independence.

## **II. Award Information**

### **1. Type of Application and Award**

Type of applications sought: New.

Funding will be provided in the form of a cooperative agreement. A cooperative agreement, as opposed to a grant, is an award instrument of financial assistance where substantial involvement is anticipated between HRSA and the recipient during performance of the contemplated project.

As a cooperative agreement, **HRSA Program involvement will include:**

- Participating, as appropriate, in meetings conducted by the National Genetics Education and Family Support Center (Family Center) during the period of the cooperative agreement;
- Collaborating with the Family Center in developing activities and procedures to be established and implemented for accomplishing the scope of work;
- Reviewing Family Center project information prior to dissemination;
- Providing assistance in establishing and facilitating effective collaborative relationships with federal and state agencies, and especially HRSA MCHB grant projects;
- Participating in disseminating Family Center project information;
- Working with the Family Center to ensure it is compliant with FOA requirements and does not duplicate the work of other MCHB-funded projects; and
- Providing relevant Family Center information resources to HRSA MCHB offices and its recipient s, and to other HRSA Bureaus relative to the program.

**The cooperative agreement recipient's responsibilities will include:**

- Conducting all tasks as they relate to the goals, objectives, and program requirements of the Family Center listed under the "Purpose" section of this FOA;
- Ensuring the integral involvement of the Regional Genetics Networks and the National Coordinating Center for the Regional Genetics Networks in the work of the Family Center;
- Reviewing, on a continuous basis, activities and procedures to be established and implemented for accomplishing the Family Center scope of work;
- Providing ongoing, timely communication and collaboration with the federal project officer;
- Working with the federal project officer to review information on Family Center project activities and products;
- Providing the federal project officer opportunity to review Family Center project information and reports prior to dissemination, e.g. report on financing and health care delivery;
- Establishing contacts that may be relevant to the Family Center's project's mission;
- Facilitating partnerships with federal and non-federal entities and other HRSA-funded programs relevant to the Family Center cooperative agreement activities; and

- Meeting deadlines for Family Center information and reports as required by the cooperative agreement and requested by HRSA.

## **2. Summary of Funding**

Approximately \$400,000 is expected to be available annually to fund one (1) recipient. You may apply for a ceiling amount of up to \$400,000 per year. The actual amount available will not be determined until enactment of the final FY 2017 federal budget. This program announcement is subject to the appropriation of funds, and is a contingency action taken to ensure that, should funds become available for this purpose, applications can be processed, and funds can be awarded in a timely manner. The project period is June 1, 2017 through May 31, 2020, three (3) years. Funding beyond the first year is dependent on the availability of appropriated funds for the National Genetics Education and Family Support Center program in subsequent fiscal years, satisfactory recipient performance, and a decision that continued funding is in the best interest of the Federal Government.

Effective December 26, 2014, all administrative and audit requirements and the cost principles that govern federal monies associated with this award are subject to the Uniform Guidance [2 CFR part 200](#) as codified by HHS at [45 CFR part 75](#), which supersedes the previous administrative and audit requirements and cost principles that govern federal monies.

## **III. Eligibility Information**

### **1. Eligible Applicants**

Per 42 CFR § 51a.3(a), any public or private entity, including an Indian tribe or tribal organization (as those terms are defined at 25 U.S.C. 450b) is eligible to apply. Faith-based and community-based organizations are eligible to apply.

An applicant may NOT apply concurrently for funding to become the lead organization for both the National Genetics Education and Family Support Center and the National Coordinating Center for the Regional Genetics Networks (HRSA-17-084); or both the Family Center and a Regional Genetics Network (HRSA-17-082). If an applicant does apply for two funding opportunities, it will be considered non-responsive and both applications will be disqualified.

Foreign entities are not eligible for HRSA awards, unless the authorizing legislation specifically authorizes awards to foreign entities or the award is for research. This exception does not extend to research training awards or construction of research facilities.

### **2. Cost Sharing/Matching**

Cost sharing/matching is not required for this program.

### 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.4* will be considered non-responsive and will not be considered for funding under this announcement.

NOTE: Multiple applications from an organization are not allowable.

If for any reason (including submitting to the wrong funding opportunity number or making corrections/updates), an application is submitted more than once prior to the application due date, HRSA will only accept your **last** validated electronic submission, under the correct funding opportunity number, prior to the Grants.gov application due date as the final and only acceptable application.

## IV. Application and Submission Information

### 1. Address to Request Application Package

HRSA **requires** applicants for this FOA to apply electronically through Grants.gov. You must download the SF-424 application package associated with this FOA following the directions provided at <http://www.grants.gov/you/apply-for-grants.html>.

### 2. Content and Form of Application Submission

Section 4 of HRSA's [SF-424 Application Guide](#) provides instructions for the budget, budget narrative, staffing plan and personnel requirements, assurances, certifications, and abstract. You must submit the information outlined in the Application Guide in addition to the program specific information below. You are responsible for reading and complying with the instructions included in HRSA's [SF-424 Application Guide](#) except where instructed in the FOA to do otherwise.

See Section 8.5 of the *Application Guide* for the Application Completeness Checklist.

#### **Application Page Limit**

The total size of all uploaded files may not exceed the equivalent of **80 pages** when printed by HRSA. The page limit includes the abstract, project and budget narratives, attachments, and letters of commitment and support required in the *Application Guide* and this FOA. Standard OMB-approved forms that are included in the application package are NOT included in the page limit. Indirect Cost Rate Agreement and proof of non-profit status (if applicable) will not be counted in the page limit. **We strongly urge you to take appropriate measures to ensure your application does not exceed the specified page limit.**

**Applications must be complete, within the specified page limit, and validated by Grants.gov under the correct funding opportunity number prior to the deadline to be considered under the announcement.**

### **Debarment, Suspension, Ineligibility, and Voluntary Exclusion Certification**

- 1) The prospective recipient certifies, by submission of this proposal, that neither it nor its principals is presently debarred, suspended, proposed for debarment, declared ineligible, or voluntarily excluded from participation in this transaction by any federal department or agency.
- 2) Where the prospective recipient is unable to attest to any of the statements in this certification, such prospective recipient shall attach an explanation to this proposal.

See Section 4.1 viii of HRSA's [SF-424 Application Guide](#) for additional information on this and other certifications.

### **Program-Specific Instructions**

In addition to application requirements and instructions in Section 4 of HRSA's [SF-424 Application Guide](#) (including the budget, budget narrative, staffing plan and personnel requirements, assurances, certifications, and abstract), please include the following:

#### ***i. Project Abstract***

See Section 4.1.ix of HRSA's [SF-424 Application Guide](#).

#### ***ii. Project Narrative***

This section provides a comprehensive framework and description of all aspects of the proposed project. 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 -- Corresponds to Section V's Review Criterion 1 (Need)***  
Briefly describe the purpose of the proposed project.
- ***NEEDS ASSESSMENT -- Corresponds to Section V's Review Criterion 1 (Need)***  
Outline the needs of the community and/or organization that will be served by the proposed project. The target population and its unmet health needs must be described and documented in this section. Disparities based on race, ethnicity, gender identity, sexual orientation, geography, socioeconomic status, disability status, primary language, health literacy, and other relevant dimensions should be considered. You should also consider people with disabilities; non-English speaking populations; lesbian, gay, bisexual, and transgender populations; people with limited health literacy; or populations that may otherwise be overlooked when identifying your target population. Include socio-cultural determinants of health and health disparities impacting the population or communities served and unmet. Demographic data should be used and cited whenever possible to support the information provided. Please discuss any relevant barriers in the service area that the project hopes to overcome.

- *METHODOLOGY -- Corresponds to Section V's Review Criterion 2 (Response)*  
Propose methods that will be used to address the stated needs and accomplish the program goals, objectives and expectations described in Section I.1 of the FOA. Be sure to describe but not limit yourself to a plan to:
  - 1) Achieve each project goal, requirement, and objective.
  - 2) Support a national web-based resource to link all patients to genetic information and services, with an emphasis on underserved populations;
  - 3) Use needs assessment data to develop and disseminate a portfolio of educational information about genetics and genetic conditions that assist families in understanding genetics and their conditions;
  - 4) Develop and disseminate a portfolio of leadership and family engagement materials to support family partnership, engagement, and leadership in the genetics care delivery system;
  - 5) Collaborate with the RGNs and NCC to reach underserved populations by:
    - a. Providing technical assistance and training on patient outreach and engagement;
    - b. Developing culturally and linguistically appropriate shared outreach materials; and
    - c. Partnering with cultural and community-based organizations to enhance outreach to underserved populations selected by the RGNs.
  - 6) Assist RGNs and NCC to recruit new family leaders for workgroups and advisory groups.
  - 7) Partner with and provide technical assistance on genetics to other MCHB family leadership programs including, but not limited to, the Family-to-Family Health Information Centers, the National Professional/Family Partnership Centers, and the Family Leadership in Language and Learning Center.

Include a plan to disseminate reports, products, and/or project outputs so project information is provided to key target audiences.

You must also propose a plan for project sustainability after the period of federal funding ends. Recipients are expected to sustain key elements of their projects, e.g., strategies or services and interventions, which have been effective in improving practices and those that have led to improved outcomes for the target population.

In addition, the proposed methods should meet the requirements and review criteria outlined in Section V of this FOA.

*WORK PLAN -- Corresponds to Section V's Review Criteria 2 (Response) and 4 (Impact)*

Submit a work plan in a table format. Describe the activities or steps that will be used to achieve each of the project objectives proposed in the methodology section. The proposed project's goals, objectives, and activities should be clearly aligned with the stated needs and meet the previously described program goals and objectives outlined in Section I.1, and requirements, and review criteria outlined in Section V of this FOA. Use a time line that includes each activity and identifies responsible staff. Use a time allocation table, graph, or chart that

includes each activity and identifies responsible staff and partners, proposed outcome, intended impact, and how the activity's outcome and impact will be measured included in Attachment 1. The reviewers should clearly be able to link the overall program objectives with the applicant's specific project goals, objectives, and activities.

Submit a Logic Model. You must submit a logic model for designing and managing your project. A logic model is a one-page diagram that presents the conceptual framework for a proposed project and explains the links among program elements. While there are many versions of logic models, for the purposes of this announcement the logic model should summarize the connections between the:

- Goals of the project (e.g., objectives, reasons for proposing the intervention, if applicable);
  - Assumptions (e.g., beliefs about how the program will work and its supporting resources. Assumptions should be based on research, best practices, and experience.);
  - Inputs (e.g., organizational profile, collaborative partners, key staff, budget, other resources);
  - Target population (e.g., the individuals to be served);
  - Activities (e.g., approach, listing key intervention, if applicable);
  - Outputs (i.e., the direct products or deliverables of program activities); and
  - Outcomes (i.e., the results of a program, typically describing a change in people or systems).
- *RESOLUTION OF CHALLENGES -- Corresponds to Section V's Review Criterion 2 (Response)*  
Discuss challenges that you are likely to encounter in designing and implementing the activities described in the work plan, and approaches that will be used to resolve such challenges.
- *EVALUATION AND TECHNICAL SUPPORT CAPACITY -- Corresponds to Section V's Review Criteria 3 Evaluative Measures and 5 (Resources/Capabilities)*  
You must describe the plan for the program performance evaluation. The program performance evaluation monitors ongoing processes and the progress towards the goals, program requirements, and objectives of the project listed under Section I.1 within this FOA. Include descriptions of the inputs (e.g., organizational profile, collaborative partners, key staff, budget, and other resources), key processes, and expected outcomes of the funded activities. Specifically, describe how the evaluation will be monitored and coordinated. Include a description of how the applicant will collect and manage data (e.g., assigned skilled staff, data management software) in a way that allows for accurate and timely reporting of performance outcomes and addresses the program objectives. Include the management of HRSA assigned DGIS and evaluation measures and region-specific projects. Explain how the data will be used to inform program development and service delivery. You must describe any potential obstacles for implementing the program performance evaluation and how those obstacles will be addressed.

Within the evaluation plan, the Family Center will be expected to provide data on how they are achieving the goals of the program and provide information on the following:

- 1) Number of families/parents/caregivers trained and serving in meaningful roles on national, regional, and local genetic service systems.
- 2) Number of families/parents/caregivers trained that report increased knowledge, skill, ability and self-efficacy to serve as leaders on genetic service systems-level teams.
- 3) Number of individuals using a national online resource of genetic information and links to services and resources.
- 4) Implementation and use of an online resource of materials and tools for all patients/families with genetic conditions:
  - a. Number of educational materials, training tools, and other resources.
  - b. Numbers and types of visitors to online resources.
  - c. Framework and tools assessed for cultural appropriateness.
- 5) Number and type of technical assistance activities to RGNs, the NCC, other family leadership program.
- 6) Number of partnerships with community organizations and other family leadership programs.
- 7) Number of families recruited for representation on advisory groups or workgroups.
- 8) Number of underserved populations receiving services.

▪ *ORGANIZATIONAL INFORMATION -- Corresponds to Section V's Review Criterion 5 (Resources/Capabilities)*

Provide information on your organization's current mission and structure, scope of current activities, and an organizational chart (Attachment 5), and describe how these all contribute to the ability of the organization to conduct the program requirements and meet program expectations. Demonstrate your experience with genetic services; in developing and disseminating genetics education and training materials in cultural and linguistically appropriate ways; in collaborating with communities, public health, and other organizations supporting individuals with genetic conditions and families

Provide information on the program's resources and capabilities to support provision of culturally and linguistically competent and health literate services. Describe current experience, skills and knowledge, including the individuals on staff that demonstrate the capability of the organization to meet the goals and requirements of this program.

You should provide a description of the organizational structure, the decision-making process and approaches that will be employed to work cooperatively with

the Regional Genetic Networks and National Coordinating Center and other partners and stakeholders. You should include an effective communication plan that ensures regular communication with NCC and RGN leadership, participation in forums and annual meeting for NCC/RGN/ Family Center key staff. You should describe responsibilities for collecting and analyzing data and how the results will be used

<b>NARRATIVE GUIDANCE</b>	
In order to ensure that the Review Criteria are fully addressed, this table provides a crosswalk between the narrative language and where each section falls within the review criteria.	
<u><b>Narrative Section</b></u>	<u><b>Review Criteria</b></u>
Introduction	(1) Need
Needs Assessment	(1) Need
Methodology	(2) Response
Work Plan	(2) Response and (4) Impact
Resolution of Challenges	(2) Response
Evaluation and Technical Support Capacity	(3) Evaluative Measures and (5) Resources/Capabilities
Organizational Information	(5) Resources/Capabilities
Budget and Budget Narrative	(6) Support Requested

**iii. Budget**

See Section 4.1.iv of HRSA’s [SF-424 Application Guide](#). Please note: the directions offered in the SF-424 Application Guide may differ from those offered by Grants.gov. Please follow the instructions included in the Application Guide and, *if applicable*, the additional budget instructions provided below.

**Reminder:** The Total Project or Program Costs are the total allowable costs (inclusive of direct **and** indirect costs) incurred by the recipient to carry out a HRSA-supported project or activity. Total project or program costs include costs charged to the award and costs borne by the recipient to satisfy a matching or cost-sharing requirement, as applicable.

In addition, the National Genetics Education and Family Support Center program requires the following:

- Travel support for annual meeting of NCC/RGN/Family Center, Program Director and Managers and HRSA.
- Quality Improvement (QI) meetings for the Regional Genetics Networks (RGN) related to the Family Center.

**iv. Budget Narrative**

See Section 4.1.v. of HRSA's [SF-424 Application Guide](#).

**v. Program-Specific Forms**

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

HRSA has modified its reporting requirements for SPRANS projects, Community Integrated Service Systems (CISS) projects, and other grant/cooperative agreement programs administered by 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, MCHB's authorizing legislation. Performance measures for other MCHB-funded grant/cooperative agreement 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 "National Genetics Education and Family Support Center".*

To inform successful applicants of their reporting requirements, the listing of MCHB administrative forms and performance measures for this program can be found in Section "VI. Award Administration Information" of this FOA.

NOTE: The performance measures and data collection information is for your PLANNING USE ONLY. These forms are not to be included as part of this application.

**vi. Attachments**

Please provide the following items in the order specified below to complete the content of the application. **Unless otherwise noted, attachments count toward the application page limit.** Indirect cost rate agreements and proof of non-profit status (if applicable) will not count toward the page limit. **Each attachment must be clearly labeled.**

*Attachment 1: Work Plan*

Attach the work plan for the project that includes all information detailed in Section IV. ii. Project Narrative. Also include the required logic model in this attachment.

*Attachment 2: Staffing Plan and Job Descriptions for Key Personnel (see Section 4.1. of HRSA's [SF-424 Application Guide](#))*

Keep each job description to one page in length as much as is possible. Include the role, 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, not to exceed two pages in length per person. In the event that a biographical sketch is included for an identified individual who is not yet hired, please include a letter of commitment from that person with the biographical sketch.

*Attachment 4: Letters of Agreement and/or Description(s) of Proposed/Existing Contracts (project-specific)*

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

*Attachment 5: Project Organizational Chart*

Provide a one-page figure that depicts the organizational structure of the project.

*Attachment 6: Tables, Charts, etc.*

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

*Attachments 7-15: Other Relevant Documents*

Include here any other documents that are relevant to the application. Letters of support must be dated and specifically indicate a commitment to the project/program (in-kind services, dollars, staff, space, equipment, etc.).

**3. Dun and Bradstreet Data Universal Numbering System (DUNS) Number and System for Award Management**

You must obtain a valid DUNS number, also known as the Unique Entity Identifier, for your organization/agency and provide that number in the application. You must also register with the System for Award Management (SAM) and continue to maintain active SAM registration with current information at all times during which you have an active federal award or an application or plan under consideration by an agency (unless the applicant is an individual or federal agency that is exempted from those requirements under 2 CFR § 25.110(b) or (c), or has an exception approved by the agency under 2 CFR § 25.110(d)).

HRSA may not make an award to an applicant until the applicant has complied with all applicable DUNS and SAM requirements and, if an applicant has not fully complied with the requirements by the time HRSA is ready to make an award, HRSA may determine that the applicant is not qualified to receive an award and use that determination as the basis for making an award to another applicant.

If you have already completed Grants.gov registration for HRSA or another federal agency, confirm that the registration is still active and that the Authorized Organization Representative (AOR) has been approved.

The Grants.gov registration process requires information in three separate systems:

- Dun and Bradstreet (<http://fedgov.dnb.com/webform/pages/CCRSearch.jsp>)
- System for Award Management (SAM) (<https://www.sam.gov>)
- Grants.gov (<http://www.grants.gov/>)

For further details, see Section 3.1 of HRSA's [SF-424 Application Guide](#).

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

#### **4. Submission Dates and Times**

##### **Application Due Date**

The due date for applications under this FOA is *December 13, 2016 at 11:59 P.M. Eastern Time.*

See Section 8.2.5 – Summary of e-mails from Grants.gov of HRSA's [SF-424 Application Guide](#) for additional information.

#### **5. Intergovernmental Review**

National Genetics Education and Family Support Center is not a program subject to the provisions of Executive Order 12372, as implemented by 45 CFR part 100.

See Section 4.1 ii of HRSA's [SF-424 Application Guide](#) for additional information.

#### **6. Funding Restrictions**

You may request funding for a project period of up to three (3) years, at no more than \$400,000 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.

Funds under this announcement may not be used for the following purposes:

- Foreign travel: Any foreign travel (using federal grant dollars or program income) must be submitted to HRSA for approval through the Electronic Hand Books (EHBs) under Prior Approval – Other.

The General Provisions in Division H of the Consolidated Appropriations Act, 2016 (P.L. 114-113) apply to this program. Please see Section 4.1 of HRSA's [SF-424 Application Guide](#) for additional information. Note that these or other restrictions will apply in FY 2017, as required by law.

You are required to have the necessary policies, procedures and financial controls in place to ensure that your organization complies with the all federal funding requirements and prohibitions such as lobbying, gun control, abortion, etc. The effectiveness of these policies, procedures and controls is subject to audit.

All program income generated as a result of awarded funds must be used for approved project-related activities.

## **7. Other Submission Requirements**

### **Notification of Intent to Apply**

You are eligible to apply even if no letter of intent is submitted. The letter should identify your organization and its intent to apply, and briefly describe the proposal to be submitted. The letter of intent should be no longer than one page. Receipt of Letters of Intent will **not** be acknowledged.

This letter should be sent via e-mail by November 1, 2016 to:

HRSA Digital Services Operation (DSO)  
Please use HRSA opportunity number as e-mail subject (HRSA-17-083)  
[HRSA\\_DSO@hrsa.gov](mailto:HRSA_DSO@hrsa.gov)

## **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 you in understanding the standards against which your application will be judged. Critical indicators have been developed for each review criterion to assist you 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.

These criteria are the basis upon which the reviewers will evaluate the application. The entire proposal will be considered during objective review.

Review criteria are used to review and rank applications. The National Genetics Education and Family Support Center has six (6) review criteria:

*Criterion 1: NEED (6 points) – Corresponds to Section IV’s Introduction and Needs Assessment*

The extent to which the application:

- demonstrates the problem and associated contributing factors to the problem (3 points);
- describes the needs of underserved populations (3 points).

*Criterion 2: RESPONSE (40 points) – Corresponds to Section IV’s Methodology, Work Plan and Resolution of Challenges*

The extent to which the proposed project responds to the “Purpose” included in the program description. The strength of the proposed goals and objectives and their relationship to the identified project. The extent to which the activities (scientific or other) described in the application are capable of addressing the problem and attaining the project objectives. The extent to which the applicant describes an effective approach to:

- Support a national web-based resource to link all patients to genetic information and services, with an emphasis on underserved populations (9 points);
- Use needs assessment data to develop and disseminate a portfolio of educational information about genetics and genetic conditions that assist families in understanding genetics and their conditions (9 points);
- Develop and disseminate a portfolio of leadership and family engagement materials to support family partnership, engagement, and leadership in the genetics care delivery system and assist RGNs and NCC to recruit new family leaders for workgroups and advisory groups (10 points);
- Collaborate with the RGNs and NCC to reach underserved populations by (9 points):
  - Providing technical assistance and training on patient outreach and engagement;
  - Developing culturally and linguistically appropriate shared outreach materials; and
  - Partnering with cultural and community-based organizations to enhance outreach to underserved populations selected by the RGNs.
- Partner with and provide technical assistance on genetics to other MCHB family leadership programs including the Family to Family Health Information Centers, the National Professional/Family Partnership Centers, and the Family Leadership in Language and Learning Center (3 points).

*Criterion 3: EVALUATIVE MEASURES (15 points) – Corresponds to Section IV’s Evaluation and Technical Support Capacity*

The strength and effectiveness of the method proposed to monitor and evaluate the project results. Evidence that the evaluative measures will be able to assess: 1) to what extent the program objectives have been met, and 2) to what extent these can be attributed to the project.

- Provides an evaluation plan that will monitor ongoing processes and the progress towards the goals, program requirements, and objectives of the award. Include

descriptions of the inputs (e.g., organizational profile, collaborative partners, key staff, budget, and other resources), key processes, and expected outcomes of the funded activities. Data collected should include the measures below.

Describes how the applicant will collect, analyze, and track the Program Specific Objective data. (7 points)

- Implementation of an online resource of materials and tools for all patients/families with genetic conditions
  - Number of educational materials, training tools, and other resources
  - Numbers and types of visitors to online resources
  - Framework and tools assessed for cultural appropriateness
- Number and type of technical assistance activities to RGNs, the NCC, other family leadership program
- Number of partnerships with community organizations and other family leadership programs
- Number of families recruited for representation on advisory groups or workgroups
- Number of unserved populations served.
- Describes the systems and processes that will support the organization's performance management requirements through effective tracking of performance outcomes, including a description of how they will collect and manage data in a way that allows for accurate and timely reporting of performance outcomes and addresses the program objectives. As appropriate, describe the data collection strategy to collect, analyze and track data to measure process and impact/outcomes and explain how the data will be used to inform program development. Describe any potential obstacles for implementing the program performance evaluation and how those obstacles will be addressed. (5 points)
- Describe current experience, skills, and knowledge, including individuals on staff, materials published, and previous work of a similar nature. (3 points)

*Criterion 4: IMPACT (14 points) – Corresponds to Section IV's Work Plan*

The degree to which:

- The feasibility and effectiveness of plans for dissemination of project results,
- The project results may be national in scope, and
- The sustainability of the program beyond the federal funding.

*Criterion 5: RESOURCES/CAPABILITIES (20 points) – Corresponds to Section IV’s Evaluation and Technical Support Capacity and Organizational Information*

The extent to which:

- The project personnel are qualified by training and/or experience to implement and carry out the project (5 points).
- The capabilities of the organization and the quality and availability of facilities and personnel to fulfill the needs and requirements of the proposed project (5 points).
- The applicant has demonstrated experience with genetic services; in developing and disseminating genetics education and training materials in cultural and linguistically appropriate ways; in collaborating with communities, public health, and other organizations supporting individuals with genetic conditions and families (10 points).

*Criterion 6: SUPPORT REQUESTED (5 points) – Corresponds to Section IV’s Budget and Budget Narrative*

The reasonableness of the proposed budget for each year of the project period in relation to the objectives, the complexity of the research activities, and the anticipated results. The extent to which the costs, as outlined in the budget and required resources sections, are reasonable given the scope of work. The extent to which key personnel have adequate time devoted to the project to achieve project objectives.

## **2. Review and Selection Process**

The objective review provides advice to the individuals responsible for making award decisions. The highest ranked applications receive priority consideration for award within available funding. In addition to the ranking based on merit criteria, HRSA approving officials also may apply other factors in award selection, (e.g., geographical distribution), if specified below in this FOA. HRSA may also consider assessment of risk and the other pre-award activities described in Section 3 below.

Please see Section 5.3 of HRSA’s [SF-424 Application Guide for more details](#).

## **3. Assessment of Risk and Other Pre-Award Activities**

The Health Resources and Services Administration may elect not to fund you with management or financial instability that directly relates to the organization’s ability to implement statutory, regulatory or other requirements ([45 CFR § 75.205](#)).

Applications receiving a favorable objective review that HRSA is considering for funding are reviewed for other considerations. These include, as applicable, cost analysis of the project/program budget, assessment of the applicant’s management systems, ensuring continued applicant eligibility, and compliance with any public policy requirements, including those requiring just-in-time submissions. You may be asked to submit additional programmatic or grants information (such as an updated budget or “other support” information) or to undertake certain activities (such as negotiation of an indirect cost rate) in anticipation of an award. However, even at this point in the process, such requests do not guarantee that an award will be made. Following review of all applicable information, the HRSA approving and business management officials will

determine whether an award can be made, if special conditions are required, and what level of funding is appropriate.

Award decisions are discretionary and are not subject to appeal to any HRSA or HHS official or board.

Effective January 1, 2016, HRSA is required to review and consider any information about the applicant that is in the [Federal Awardee Performance and Integrity Information System \(FAPIS\)](#). An applicant may review and comment on any information about itself that a federal awarding agency previously entered. HRSA will consider any comments by the applicant, in addition to other information in [FAPIS](#) in making a judgment about the applicant's integrity, business ethics, and record of performance under federal awards when completing the review of risk posed by you as described in [45 CFR § 75.205 HHS Awarding Agency Review of Risk Posed by You](#).

A determination that an applicant is not qualified will be reported by HRSA to FAPIS (45 CFR § 75.212).

#### **4. Anticipated Announcement and Award Dates**

HRSA anticipates issuing/announcing awards prior to the start date of June 1, 2017.

## **VI. Award Administration Information**

### **1. Award Notices**

HRSA will issue the Notice of Award prior to the start date of June 1, 2017. See Section 5.4 of HRSA's [SF-424 Application Guide](#) for additional information.

### **2. Administrative and National Policy Requirements**

See Section 2 of HRSA's [SF-424 Application Guide](#).

#### **Human Subjects Protection:**

Federal regulations (45 CFR part 46) require that applications and proposals involving human subjects must be evaluated with reference to the risks to the subjects, the adequacy of protection against these risks, the potential benefits of the research to the subjects and others, and the importance of the knowledge gained or to be gained. If research involving human subjects is anticipated, recipients must meet the requirements of the HHS regulations to protect human subjects from research risks as specified in the Code of Federal Regulations, Title 45 – Public Welfare, Part 46 – Protection of Human Subjects (45 CFR part 46), available online at <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html>.

### 3. Reporting

On June 10, 2016, the Office of Management and Budget approved MCHB to collect new performance measures from recipients as part of its Discretionary Grant Information System (DGIS). The new performance measures reflect MCHB's strategic and priority areas including financial and demographic information, health domain and program-specific measures, and program-specific measures that highlight the unique characteristics of discretionary grant projects that are not already captured. Collectively, these data communicate the MCHB "story" to a broad range of stakeholders on the role of the Bureau in addressing the needs of maternal and child health populations. These performance data will also serve several purposes, including recipient monitoring, performance reporting, MCHB program planning, and the ability to demonstrate alignment between MCHB discretionary programs and the MCH Title V Block Grant program.

These new performance measures will allow a more accurate and detailed picture of the full scope of activities supported by MCHB-administered grant/cooperative agreement programs, while reducing the overall number of performance measures from what was previously used. The MCHB Project Officer will assign a subset of measures relevant to the program for which the recipients will report. In addition to reporting on the new performance measures, recipients will continue to provide financial and program data. The new reporting package can be reviewed at: [http://mchb.hrsa.gov/sites/default/files/mchb/Data/Discretionary\\_Grant\\_Information\\_System\\_Performance\\_Measure\\_Update.pdf](http://mchb.hrsa.gov/sites/default/files/mchb/Data/Discretionary_Grant_Information_System_Performance_Measure_Update.pdf).

New and continuing awards issued on or after October 1, 2016, will be required to report on the new measures. For successful competing continuation awards, recipients will report on their previous year activities (defined as those completed before October 1, 2016) using the forms and measures in DGIS as assigned in the previous FOA.

The successful applicant under this FOA must comply with Section 6 of HRSA's [SF-424 Application Guide](#) and the following reporting and review activities:

- 1) **Progress Report(s).** The recipient must submit a progress report to HRSA on an **annual** basis. Further information will be provided in the award notice.
- 2) **Final Report Narrative.** The recipient must submit a final report narrative to HRSA after the conclusion of the project.
- 3) **Performance Reports.** HRSA has modified its reporting requirements for SPRANS projects, CISS projects, and other grant/cooperative agreement programs administered by 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, MCHB's authorizing legislation.

### **a) Performance Measures and Program Data**

After the NoA is released, the MCHB Project Officer will inform recipients of the administrative forms and performances measures they must report.

### **b) Performance Reporting Timeline**

Successful applicants receiving HRSA 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 are required for this award. This requirement entails the provision of budget breakdowns in the financial forms based on the award amount, the project abstract and other grant/cooperative agreement summary data as well as providing objectives for the performance measures.

Performance reporting is conducted for each year of the project period. Recipients 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/cooperative agreement summary data as well as finalizing indicators/scores for the performance measures.

### **c) Project Period End Performance Reporting**

Successful applicants receiving HRSA funding will be required, within 90 days from the end of the project period, to electronically complete the program-specific data forms that appear for this program. The requirement includes providing expenditure data for the final year of the project period, the project abstract and grant/cooperative agreement summary data as well as final indicators/scores for the performance measures.

4) **Integrity and Performance Reporting.** The Notice of Award will contain a provision for integrity and performance reporting in [FAPIS](#), as required in [45 CFR part 75 Appendix XII](#).

## **VII. Agency Contacts**

You may obtain additional information regarding business, administrative, or fiscal issues related to this FOA by contacting:

Devon Cumberbatch  
Grants Management Specialist  
Division of Grants Management Operations, OFAM MCHB  
Health Resources and Services Administration  
5600 Fishers Lane  
Rockville, MD 20857  
Telephone: (301) 443-7532

E-mail: [DCumberbatch@hrsa.gov](mailto:DCumberbatch@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, ScM  
Project Officer  
Attn: Genetic Services Branch  
Maternal and Child Health Bureau  
Health Resources and Services Administration  
5600 Fishers Lane, Room 18W09D  
Rockville, MD 20857  
Telephone: (301) 443-3247  
E-mail: [JShuger@hrsa.gov](mailto:JShuger@hrsa.gov)

You may need assistance when working online to submit your application forms electronically. You 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 (International Callers, please dial 606-545-5035)  
E-mail: [support@grants.gov](mailto:support@grants.gov)  
Self-Service Knowledge Base: <https://grants-portal.psc.gov/Welcome.aspx?pt=Grants>

Successful applicants/recipients may need assistance when working online to submit information and reports electronically through HRSA's Electronic Handbooks (EHBs). For assistance with submitting information in HRSA's EHBs, contact the HRSA Contact Center, Monday-Friday, 8:00 a.m. to 8:00 p.m. ET, excluding federal holidays at:

HRSA Contact Center  
Telephone: (877) 464-4772  
TTY: (877) 897-9910  
Web: <http://www.hrsa.gov/about/contact/ehbhelp.aspx>

## **VIII. Other Information**

### **Logic Models:**

Additional information on developing logic models can be found at the following website: <http://www.cdc.gov/eval/resources/>.

Although there are similarities, a logic model is not a work plan. A work plan is an "action" guide with a time line used during program implementation; the work plan provides the "how to" steps. Information on how to distinguish between a logic model and work plan can be found at the following website: <http://www.cdc.gov/healthyouth/evaluation/pdf/brief5.pdf>.

**Technical Assistance:**

MCHB will host a pre-submission technical assistance webinar for all prospective applicants on October 27, 2016 at 3:00 – 4:00 pm Eastern Time. Call details are as follows:

Time: 3:00 - 4:00 pm ET

Dial-in: 1-866-723-0810; Participants Passcode 31341820

Web Link: <https://hrsa.connectsolutions.com/nesc>

**IX. Tips for Writing a Strong Application**

See Section 4.7 of HRSA's [SF-424 Application Guide](#).