



**The Genetics
Education Needs
Evaluation Project**

Final Report
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Executive Summary

Statement of the Problem

Advances in genetics have created new opportunities for improvements in health care. For the public to benefit from these opportunities, access to information, genetic screening, testing, genetic counseling, and other genetic services¹ that are community-based and culturally appropriate must be readily available. Unfortunately, public awareness of and knowledge about this complex health issue is low and individuals from underserved and under-represented communities² face additional linguistic and cultural barriers to genetic information and services. Although many consumer advocacy organizations and government agencies have developed informational materials about genetics, this information can be difficult to access and understand. Moreover, the information may not be culturally and linguistically appropriate for all individuals.

Healthcare providers, a primary source of medical information, often lack the training and the time to provide adequate genetic information, counseling, referrals to genetics professionals (including genetic counselors and geneticists), and interpretation of test results. In addition, few genetics professionals are from underserved and under-represented communities. The services and counseling offered by these providers may not fully consider an individual's language, beliefs, values, and experiences based on his or her ethnic/racial background, country of origin, and immigration history.

Overview of the GENE Project

To help address this problem, the Genetic Services Branch of the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA) funded a 5-year cooperative agreement with the March of Dimes (MOD), called the Genetics

¹Genetic services include genetic screening, evaluation (a medical examination to identify symptoms or features of a genetic disorder), testing (analysis of human DNA, RNA, chromosomes, or proteins to detect disease or susceptibility to disease), genetic counseling, follow-up medical care for people affected by a genetic condition, and genetic education (adapted from the Washington Department of Health and the Genetic Services Branch, MCHB, HRSA).

² The term 'underserved and under-represented populations' can include many groups, but this project focused on people who face ethno-cultural and other barriers to care, including ethnic/racial minorities, recent immigrants, and refugees.

Education Needs Evaluation (GENE) Project. The Genetic Services Branch focuses on ways to improve the early identification of individuals with or at risk for heritable conditions, and an understanding of the genetic contribution to health and disease upon which health services are developed. The March of Dimes is a nationally recognized non-profit consumer health organization that provides education, research and advocacy in maternal and child health, with enduring programmatic emphasis on the use of genetics to improve health. Two other national organizations were also partners³ in the project: Family Voices (a national grassroots network of families speaking on behalf of children and youth with special health needs), and the Genetic Alliance (a coalition of consumers and professionals that promotes the interests of children, adults, and families living with genetic conditions). Community partners included the African-American communities in Flint/Lansing, Michigan, and the Latino communities in Washington Heights/Inwood, New York.

The central mission of the project was to develop community-based participatory strategies to improve access to culturally and linguistically appropriate genetics information, resources, and services to assist underserved and under-represented populations in making informed choices about their health. The long-range vision of the GENE project was to create a collaborative network for the development and dissemination of culturally appropriate genetic information that would assist individuals and groups in making inquiries and informed choices about health. Specific goals were as follows:

1. To strengthen and expand existing partnerships⁴ between the Health Resources and Services Administration, March of Dimes, Family Voices, and Genetic Alliance to develop, sustain and replicate a model of genetics education⁵ with and for populations who are underserved and under-represented.
2. To develop a model of community-based participatory consumer genetics education strategies. Steps include: partnering with two communities, developing local coalitions, identifying community needs and strengths, developing educational messages and strategies, and evaluating and synthesizing the experiences.

³ The GENE Project used the term “partner” to refer to an entity or representative of an entity involved in the project via a contractual mechanism and/or memorandum of understanding.

⁴ At an in-person meeting in May 2003, the GENE Project partners defined a “partnership” as follows: “Partnership begins with communication that facilitates relationship building that leads to trust, understanding, and common vision.”

⁵ The project defined genetics education as the gradual process of acquiring information about genetics such as information about genes, inherited characteristics, and how it applies to health and health decisions. Educational methods can include individual encounters, group meetings, print media, presentations, Internet, or other media.

3. Building on the community involvement, to disseminate and replicate the model of community-based participatory consumer genetics education strategies.
4. To increase participation of community members in public health policy initiatives regarding genetics.

The major project components to achieve these goals included: (1) literature reviews and other needs assessment activities, (2) community-based projects that engaged local partners to assess and address genetics information needs in their communities, and (3) dissemination of the results of these community projects for replication by other organizations.

History and Approach

The GENE Project underwent substantial restructuring during the first few years to refine the project goals and objectives so that they were achievable within the timeframe and budget allotted. The emphasis of the project changed from a sweeping national

**Community-based
Participatory Action Research**

- ❖ **Is action oriented**
- ❖ **Involves ordinary people in the collective investigation of community problems during the entire process of research**
- ❖ **Seeks solutions to community problems through partnerships and collaborations**
- ❖ **Emphasizes engagement and mobilization of a variety of community stakeholders**
- ❖ **Builds capacity through development of coalitions and training**
- ❖ **Embraces personal and community empowerment**

Source: Aida Giachello

initiative focusing on network and educational materials development to a focused, community-based initiative in underserved and under-represented communities. This emphasis on communities and underserved populations was chosen because of the Maternal and Child Health Bureau's priority to address health disparities and to use consumer involvement and community-based approaches in addressing them. The GENE Project's community-based approach was based on the conceptualization provided by the

Genetic Services Branch, MCHB, HRSA. The process for implementation was provided by an expert consultant hired by MOD—Dr. Aida Giachello from the Midwest Latino Research Center, University of Illinois.

A major component of the GENE Project's approach was its focus on creating partnerships among and between national organizations and the two communities. This

project provided the opportunity for the four national organizations (Family Voices, Genetic Alliance, March of Dimes, and HRSA) to form relationships, gain experience in effective collaboration, and identify strategies for effective local outreach and education. HRSA identified these national organizations as potential partners because each represented different parts of the maternal and child health population and each organization had networks of state and/or local representatives. Partnerships among these organizations at the national, state, and/or local level were intended to (1) leverage limited resources to meet the public's education and access to resource needs and (2) help all partners gain knowledge and experience in outreach to underserved and under-represented communities.

Other project participants included:

- Community partners: Washington Heights/Inwood, NY and Flint/Lansing, MI;
- Policy/research consulting firms such as LTG Associates, Clinical Directors' Network, Hastings Center;
- Consultant for technical assistance to communities: Dr. Aida Giachello;
- External evaluator: Abt Associates Inc.;
- Community evaluators; and
- A project Advisory Committee.

Activities and Accomplishments

The GENE Project accomplished its major goals and activities in two phases: an information-gathering phase (Years 1-3) and a community project phase (Years 4-5) (Exhibit 1).

MOD hired several different consulting firms to conduct a wide range of activities during Years 1-3 of the project in order to inform the implementation of the GENE project. The variety of methods used to gather information provided a fairly complete picture of the needs, best practices, and history of what was known to date about genetics education and underserved and under-represented populations. These activities (1) described and confirmed the need for genetics education in underserved and under-represented communities and for education strategies that are culturally/linguistically appropriate; (2) described the challenges in developing educational materials on genetics that are culturally appropriate and address the ethical, legal, and social concerns related to genetic technologies; (3) provided examples of lessons learned and critical success

factors; (4) demonstrated the gaps in knowledge that the GENE Project could fill; and (5) underscored the importance of participation in genetics policy development by minority communities.

Exhibit 1

Phase 1 Activities	Phase 2 Activities
<ul style="list-style-type: none"> • Literature reviews on the genetics education needs of (1) consumers in general and of (2) underserved and under-represented communities; • A concept paper on “genetic citizenship;” • Interviews with consumer advocacy organizations for genetic conditions; • Meeting between GENE Project participants and former HRSA grantees who had similar community-based projects to share lessons learned; • Focus groups with consumers from underserved and under-represented populations. 	<ul style="list-style-type: none"> • Selection and engagement of two communities to participate in the GENE project; • Development of a local coalition or community advisory board in these communities; • Needs/assets assessments conducted by the communities; • Development of a plan for implementing education and outreach strategies to respond to the identified needs; • Dissemination of the results of the community projects to the communities themselves and to broader regional and national audiences, including policy-makers.

Each community successfully conducted needs/assets assessments for genetics education, which confirmed the need for education/outreach to the African-American and Latino communities. Although MOD and HRSA had initially anticipated that a single, replicable model for genetics education in underserved and under-represented communities would emerge from the two community projects, the communities developed differing approaches based on what was most appropriate to the context in each community, including the cultural background of community members and the readiness of the communities to address genetics education (Exhibit 2). While both communities relied on ties with community-based organizations and a combination of quantitative and qualitative strategies, the Michigan GENE Project chose a community dialogue process and Washington Heights/Inwood conducted a survey of community members, complemented by focus groups with local residents and with providers of genetic services.

Exhibit 2 Summary of Community Project Strategies and Accomplishments

Washington Heights/Inwood GENE Project	Michigan GENE Project
<ul style="list-style-type: none"> • Focused on Latino (predominantly Dominican) community • Developed a new coalition with no prior experience with genetics initiatives • Led by Dominican Women's Development Center, a community-based organization • Used survey and focus groups to assess needs/assets • Local evaluation focused on implementation and effectiveness of the coalition • Action plan included community discussions and educational sessions, development of a Spanish/English DVD entitled "Genetics & Your Health 101," compiling a directory of genetic services, press releases, quarterly newspaper, advocate for more bilingual genetic service providers and train others on genetics and cultural issues 	<ul style="list-style-type: none"> • Focused on African-American community • Used community advisory board (CAB) that had two prior genetics initiatives • Led by Michigan State University • Used community dialogue process to assess needs/assets • Local evaluation focused on process of completing deliverables, CAB member motivation and time spent, and satisfaction of Town Hall participants • Action plan included the development of culturally appropriate educational materials, genetic education seminars, some aimed at young African Americans to steer them toward science careers

The results of the needs/assets assessments indicated the need for information about genetics and genetic services, and identified barriers to genetic services and potential strategies for education and outreach. In both communities, (1) awareness and knowledge of genetics and genetic services were low, (2) few community members had ever received services that they would characterize as genetic services, and (3) interest in learning more about genetics was high. A major barrier in each community was the lack of access to genetic counseling services. In the case of Flint/Lansing, there were no genetic counselors. In the case of Washington Heights/Inwood, there were an inadequate number of bilingual genetics health professionals. Many participants in the Flint/Lansing dialogue process expressed mistrust of genetic research and feared that genetic information could be used to discriminate against African Americans. They also wanted young African Americans to have access to genetic education in schools and the opportunity to pursue careers in genetics. In Washington Heights/Inwood, genetic counselors reported that many of their prenatal Latino patients delayed coming to their appointments because they did not understand the reason for a referral and were fearful

that they would be forced to undergo a painful and dangerous procedure. In general, healthcare providers who were not bilingual had difficulty earning the trust of their Latino patients. Communities created action plans with recommendations for developing education/outreach strategies based on the results of these assessments (see below).

The evaluation of the overall GENE Project also examined the degree to which collaboration and partnership development occurred as a result of GENE activities as well as the knowledge gained by participants on genetics and each others' organizations.

One of the most significant accomplishments of the GENE Project was that several national and community organizations developed new partnerships.

Several collaborative efforts outside the GENE Project were initiated or enhanced as a result of the GENE Project such as Project Connect, a HRSA-funded cooperative agreement with the Genetic Alliance that also focused on outreach and genetics education of underserved and under-represented communities. The national and community partners contributed to the success of Project Connect in 2004 by helping the Genetic Alliance develop a workshop on outreach and identify appropriate individuals from underserved and under-represented communities to attend the Genetic Alliance's annual conference (one objective of Project Connect). Some of the attendees eventually joined the Project Connect network.

Using the participatory approach, the project engaged community representatives and members in all activities, although to varying degrees. While the GENE Project generally adhered to the principles of the participatory approach, partners found the approach resource- and time-intensive. In addition, the theory and definitions of the approach were new and unfamiliar to some participants and thus required additional time and clarification to implement effectively. Because partners were often unclear on the decision-making authority and specific expectations, memoranda of understanding and contracts were revisited to adequately reflect evolving roles and expectations and a Partnership Agreement was developed to further clarify levels of involvement. Keeping with the participatory approach, the communities had ownership over their own needs/assets assessments and were provided technical assistance as needed. Finally, different partners desired varying degrees of participation and oversight from HRSA and MOD in the project.

The degree to which partnerships developed between the communities and each of the national organizations depended on the needs of the community, the geographic distance, the services and skills the representatives of the national organizations could provide (and their appropriateness to that community), and the level of trust among the people involved.

The local evaluations provided additional detail on the processes and outcomes of the GENE project in each of the communities and concluded that the communities were successful in (1) engaging community members in genetics education needs assessment processes, (2) developing models for communicating findings to the community, and (3) developing action plans that included ideas and models for genetics education that were responsive to the knowledge level of the communities and that were culturally and linguistically relevant.

Through the GENE Project, all of the participants became more familiar with each other's organizations, and they shared resources such as upcoming grant opportunities, conferences, publications and websites. Information and resources were shared primarily through presentations at in-person meetings, conference calls, and the project listserv. As the project evolved, partners learned more about relevant resources or skills that each had to offer.

By the end of the project period, partners at the community and national level demonstrated increased knowledge with regard to participatory strategies, genetics, and data collection and analysis methods to assess the needs/assets of the communities (focus groups, interviews, surveys, etc.). Project partners increased their awareness of genetic information and resource needs in African American and Latino communities, barriers to genetics education and service utilization, and strategies for creating culturally appropriate genetics information.

Critical Success Factors

At the national project level, factors related to partnership building were critical to the success of the project:

- Having a shared commitment to the mission of the project—to improve genetics education for underserved and under-represented communities;
- Documenting roles and expectations, and updating them in response to changes in project requirements;
- Communicating regularly, especially through in-person meetings;
- Demonstrating respect and building trust.

Factors that were critical to the success of community projects included:

- Communicating in a respectful, clear, and consistent manner, especially via face-to-face meetings to establish trust;

- Having someone in the community/organization who had a deep personal interest in, or curiosity about, genetics;
- Involving organizations with community networks and expertise in community organizing;
- Involving the federal government and other national partners for both the additional resources (e.g., genetics information, training capacity, technical assistance for research activities) as well as increased credibility in the community.

Challenges

- The complexity of the participatory approach and the resources required were underestimated.
- The lack of clarity in the roles of HRSA and MOD in the cooperative agreement often affected other partners, who anticipated more guidance from HRSA in explaining the vision and expectations for the project or wondered who had ultimate decision-making authority.
- Changes in nongovernmental organizations' project leadership and representatives resulted in setbacks in partnership development, and may have been one reason why partners needed frequent clarification of their roles and responsibilities.
- For March of Dimes, Family Voices and Genetic Alliance, using local representatives was, overall, challenging to arrange, and difficult to sustain over time.
- The results of local evaluations in Washington Heights/Inwood and Michigan revealed challenges with how best to develop a coalition/community advisory board, including: recruitment and retention of members, lack of time among members to participate more fully, and how to balance the need to build infrastructure with program implementation.

Lessons Learned

- While the GENE Project built structures that positioned them to create strong partnerships, the evolution of relationships was hindered due to

limited time as well as limited experience operationalizing a participatory project.

- Communication between and among various partners required a lot of different strategies and resources and much trial and error to achieve a balance between effective communication and prevent overburdening partners.
- Relationship building is fundamental to creating an effective partnership network. Relationships need to be continuously fostered, especially via face-to-face communication, at all levels, especially at the project representative level and community-coalition level. Successful methods used to develop relationships included alternating the site of project meetings among partners and sharing information about each other's communities and cultures.
- Although MOD attempted to define their relationships with individual partners, it became clear that a more comprehensive, transparent approach to clarifying partnership roles and responsibilities across all organizational entities was required, such as a "partnership agreement."
- The participatory approach can be successfully used to implement genetics education initiatives, but should be considered a continuum and not "one size fits all." Different partners and communities often desired different levels of participation in project activities, had different areas of interest, and varied preferences for approaches/strategies to use.
- Despite the social and economic hardships that underserved/under-represented communities face, they are interested in knowing more about genetics and how it affects them.

Recommendations

Each community project developed recommendations for addressing the genetics education needs identified in their needs/assets assessments. To address the low level of knowledge about genetics and access to services, the Washington Heights/Inwood coalition identified several priorities and developed an action plan with the following strategies and recommendations: (1) conduct group discussions and educational sessions for community members led by local genetics professionals (to date, several of these have already occurred), (2) develop a Spanish/English DVD entitled "Genetics and Your Health 101," (3) launch a quarterly newspaper article dedicated to topics on

genetics and health, (4) assemble a directory of available genetic services, and (5) distribute press releases to community members on project activities. The other priorities set by the coalition were to improve the quality and cultural competency of these services by advocating for an increase in the number of bilingual genetic service providers in local hospitals and for an enhancement in community hospital capacity. In addition, it would reach out to local healthcare providers to get training in genetics and cultural matters. Finally, the coalition would strive to expand, or at least maintain, its membership volume and to sustain its activities. In order to support and extend its activities, it would seek additional funding from private foundations and government agencies.

Findings from Michigan's community dialogue process formed the basis of a five-year action plan. With the assistance of experts in genetics, Michigan's Community Advisory Board (CAB) planned to develop culturally appropriate educational materials. These materials would be disseminated to community residents with the goal of improving awareness about and access to genetic services. In collaboration with the community-based organizations, the CAB would host genetic education seminars for African Americans and develop their advocacy skills. By exposing young African Americans to the field of genetics through discussions of possible career opportunities, the CAB would work to steer them toward careers in science. To date, the Michigan CAB has worked with a genetic counselor to conduct two genetic education sessions in a local elementary school in Lansing.

Based on the experience of the GENE Project, we have the following recommendations for others trying to replicate the project. Some of these are also relevant for the next five years of the GENE Project.

- Define “participatory” at the onset of the project and elicit the level of participation desired by each partner.
- Clarify partner roles in the beginning of the project and throughout the course of the project.
- In order to achieve cohesive, collaborative groups, provide opportunities for partners to get to know each other on a personal level, through in-person meetings that include meals and social events, for example.
- Make communication transparent and establish clear rules regarding how, and to whom, information is transmitted.
- When identifying national organizations for partnership, consider the capacity of the national organizations at the local level to provide the

infrastructure, time, expertise, and culturally appropriate representatives necessary to work effectively with communities.

- Provide partners with adequate resources and guidance to enable them to fully engage with communities.
- Assess community readiness and needs for technical assistance in the beginning of the project in order to determine which supports and structures need to be put in place to promote successful implementation.
- When project representatives from an organizational partner change, ensure smooth transitions through proactive efforts.
- Ensure that representatives of participating organizations are culturally sensitive and engage in appropriate behavior that respects project participants.
- In the early stages of a project, carefully consider the structure and functions of a community advisory board or coalition, due to the impact on the timeline and resource requirements to recruit and maintain membership.

The GENE Project was unique among genetics initiatives in its use of the participatory approach in its activities such as research and community engagement strategies to identify the genetics education needs of underserved and under-represented communities. As a result of this initiative, much more is known about the genetics information and service needs of African-Americans and Latinos, such as their interest in learning more about genetics related to healthcare decision-making. Partnerships between national advocacy organizations and communities increased genetics knowledge among community advisory board/coalition members, informed the design of the needs/assets assessments, and contributed to viable genetics education action plans. The lessons learned from the GENE Project should enable other national, state, and community organizations to plan and implement similar initiatives.