

Community Genetics Education Network (CGEN)

**National Evaluation Phase II Report:
Implementation and Evaluation
January 2007- June 2010**

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EXECUTIVE SUMMARY

Background

In 2005, the U.S. Health Resources and Services Administration (HRSA) funded a five-year cooperative agreement with the March of Dimes called the Community Genetics Education Network (CGEN) project. The overall goal of the CGEN project was to increase the genetic literacy of African Americans, Latinos, Asian Americans, and Pacific Islanders, in order to promote:

- Informed health decision-making;
- Consultation with family and health care providers about genetics and health;
- Use of genetics services among high-risk populations; and
- Adoption of lifestyle changes to reduce genetic-based health risks.

The CGEN project applied principles of community-based participatory research (CBPR) to develop, plan, implement, evaluate, and disseminate culturally and linguistically appropriate genetics education interventions and materials for low-literacy populations of diverse cultural backgrounds. Four sites engaged in these processes with selected target communities.

Specifically:

1. The Charles B. Wang Community Health Center (**CBWCHC**) in New York City developed and implemented Chinese-language genetics education workshops for at-risk prenatal patients, prior to their meeting with a genetic counselor. CBWCHC also produced five Chinese/English bilingual brochures and two Korean/English bilingual brochures on topics related to genetics and health.
2. The Dominican Women's Development Center (**DWDC**) in the Washington Heights/Inwood section of New York City developed and implemented a bilingual (Spanish/English) genetics education curriculum for Community Health Workers (CHWs) or *promotores/as de salud* (health promoters). The CHWs in turn used the project's bilingual materials to deliver genetics education workshops to community members.
3. The National Human Genome Center and Department of Community and Family Medicine at Howard University (**Howard**) in Washington, DC developed two interactive booklets, "Race, Genetics and Health" and "Planning for a Healthy Future: The Importance of Family Health History" and used them in community workshops with African Americans. They also created an associated toll-free informational number and website.
4. The Genetic Science Learning Center at the University of Utah, in partnership with the Utah Department of Health Chronic Disease Genomics Program (**Utah**), Salt Lake City, developed and implemented bilingual genetics education curricula and materials for fifth grade students (Spanish/English), secondary school students (Spanish/English), and Tongan adults (Tongan/English). They also produced related educational materials for general audiences.

These sites represented—and/or had access to—underserved racial and ethnic minority group populations, had completed genetics needs and assets assessments in the target communities prior to CGEN project initiation, and had track records of implementing community genetics education activities.

Throughout the CGEN project, all sites had a local project coordinator, a local project evaluator, and one or two local community advisory boards (CABs). The CABs' role was to provide community-based input to the development, planning, implementation, evaluation, dissemination, and sustainability of local CGEN interventions and materials. Additionally, a national evaluation team based at the Midwest Latino Health Research, Training and Policy Center, University of Illinois at Chicago, provided evaluation guidance and oversight.

The March of Dimes served as the overall project coordinating center. In this capacity, March of Dimes provided project management, technical assistance, quality assurance, and general guidance, and it worked to foster and enhance collaboration among the CGEN project partners as well as promote relationships with other organizations. The HRSA Project Officer took an active role throughout the project by attending meetings, providing feedback on major deliverables, and circulating information about training events, funding announcements, conferences, and publication opportunities that supported the goals and activities of the CGEN partners.

The CGEN project was implemented in several (overlapping) phases:

- Phase I – Partnership formation, program planning, and development.
- Phase II – Community awareness and education, including implementation and evaluation of culturally and linguistically appropriate genetics education interventions.
- Phase III – Dissemination of interventions, educational materials, and best practices to other sites and the broader field, and institutionalization/sustainability of promising practices in CGEN sites.

This national evaluation report provides a descriptive synthesis and a largely qualitative, thematic analysis of the activities, outcomes, and learnings of the CGEN project's **Phase II**, implementation and evaluation of culturally and linguistically appropriate genetics education interventions in the four community sites. This phase began as early as December 2006 or the first quarter of 2007 for several interventions, and for a number of interventions Phase II activities continued into the first three quarters of 2010. For most sites, an initial implementation and evaluation pilot study was followed by a period of revisions to procedures and materials and then a second pilot study.

The data sources for this report included local project coordinator, local evaluator, and national evaluation reports; conference call and in-person meeting minutes; CGEN American Public Health Association (APHA) Annual Meeting slidesets; other CGEN historical documents; and ongoing discussions among team members. The objective of the report is not to provide exhaustive detail on the implementation practices or evaluation methods or findings of each local intervention, as such information is available in local site reports. Instead, the present report focuses on summarizing methods and findings and deriving overall challenges, strategies, and best practice implications that emerged from the review of local and national Phase II efforts.

Local Evaluation Methodologies

All local evaluations had some common requirements and expectations, including IRB approval, development of logic models (i.e., visual representations of local project inputs, activities, outputs, and desired outcomes), implementation of both process and outcome evaluation activities, and a CBPR approach that included CAB and/or other community constituent involvement. While there was also initially an intent to collect data on some common indicators across all local projects, using a common core set of survey items, these plans were abandoned due to the local sites' divergent populations, interventions, and timelines. The local and national evaluators experienced a number of challenges related to cross-site requirements and expectations. These are discussed further below.

Project coordinators had responsibility for identifying implementation sites to test their major CGEN interventions (i.e., classroom-based programs and clinic- and community-based workshops), and for overseeing the implementation or deployment process for all of their CGEN interventions and related CGEN resources (i.e., brochures, toll-free number, website). Local evaluators had responsibility for conducting (or overseeing) data collection and for analyzing data and reporting on findings. Local sites were charged with conducting both process and outcome evaluation for the pilot tests of their major interventions. The evaluation designs and methods of these major interventions are summarized in Table A. Overall, the most common outcome evaluation methodology employed was pre- and post-test surveys with intervention participants. One site included a control group for its workshops, and another site compared outcomes from two versions of a school-based intervention (i.e., one with and one without a video component). Sites collected only basic process data on the additional resources (brochures, toll-free number, website) that supported these interventions and served as stand-alone resources. The methods they used collectively included focus groups, logs, and a usage survey.

Local Evaluation Findings

Evaluation sample sizes and outcome findings are summarized in Table B. Overall, across the CGEN interventions, evaluation participation rates were generally high, and most sites had relatively low rates of missing data. Many pilot evaluations had largely positive process evaluation findings that showed that sites had essentially delivered the intended services, activities, or materials to the targeted racial/ethnic and geographic groups and for the most part had reached the targeted number of participants. Participant feedback on the interventions and materials was overwhelmingly positive, and also often included helpful suggestions for improvements. A number of the training/educational workshops did experience some difficulty delivering workshop content consistently. Shorter-than-intended workshop slots, diverse baseline knowledge and interests among participants, and the need for time to complete evaluation-related procedures presented particular challenges. Additional training for workshop facilitators appeared to help address these challenges. One site also experienced particular difficulty reaching the intended target population in an initial pilot study; closer collaboration with CAB members, the local March of Dimes Chapter, and other local agencies helped to ensure greater participation of the targeted population in a second pilot study.

Table A. Evaluation Designs and Methods: Major Interventions

Site	Intervention Approach	Target N	Process Evaluation					Outcome Evaluation				
			Participant Attendance	Participant Demographics	Participant Satisfaction	Topics/activities Checklist	Staff Satisfaction or Other Implem. Assessment	Pre/ Post Partic. Survey	Mid-Term Partic. Follow-up	Comparison Group	Assessment of Partic. Outcomes	Staff Assessment of Partic. Outcomes
CBWCHC	Clinic-based pre-counseling workshops	40 patients-treatment group 40 patients-control group ¹	X	X	X			X		X	X (genetic counselor survey ²)	X ³
DWDC	Training of CHWs	12 CHWs	X	X	X			X	*			
	Community workshops	250 adults	X	X	X	X	X (CHW/ observer survey)	X	*			
Howard	Community workshops	Pilot 1: 100 adults (50-75 for eval.) Pilot 2: 100 adults for eval.	X	X	X	X	X (facilitator survey)	X	X			
Utah	5th grade curriculum & materials	4 teachers 100 students		X	X		X (teacher survey; students asked if hmwrk done) ⁴	X			X (teacher survey ⁵)	
	Secondary school materials	6 teachers 420 students		X	X		X (teacher survey; students asked if hmwrk done) ⁴	X		X ⁶	X (teacher survey ⁵)	
	Community workshops	100 adults	X	X	X			X				

Notes:

* Originally planned but later dropped.

¹ These were the target numbers for the third pilot (June-November 2009).

² Genetic counselor was asked to provide her impressions of patient learning.

³ Length of appointment with genetic counselor (examined for a subset of evaluation participants only).

⁴ Homework assignments involved sharing class materials with family members.

⁵ Classroom teachers were asked to provide their impressions of student learning.

⁶ For video component only.

Table B. Summary of Evaluation Sample Sizes and Outcome Evaluation Findings

Sites	Intervention Approach	Evaluation N	Knowledge	Attitudes, Self-Efficacy, &/or Beliefs	Satisfaction w/ Subsequent Care	Intentions	Health Behaviors	Other
CBWCHC	Clinic-based workshops	86 ¹ (44 I, 42 C)	++ (I vs. C, pre to post)	++ (I vs. C, pre to post)	NS (I vs. C, post only)	N/A	N/A	+ (length of appt. w/ gen. counselor, I vs. C)
DWDC ²	Community workshops: Pilot 1	114 adults	++ ³	N/A	N/A	++	N/A	N/A
	Community workshops: Pilot 2	133 adults	++	N/A	N/A	++	N/A	N/A
Howard ⁴	Community workshops: Pilot 1	178 adults	++ ⁵ (pre to post)	N/A	N/A	+ (post only)	+ (pledge fulfillment; post only)	N/A
	Community workshops: Pilot 2	183 adults	++ ⁶ (pre to post)	N/A	N/A	+ (post only)	+/- ⁷ (pledge fulfillment; stages of change)	N/A
Utah	Fifth grade curriculum/materials	6 teachers; 159 students for outcomes; 169 students for satisfaction	++ (pre to post)	++ (confidence in knowledge) + (interest to learn more; post only)	N/A	N/A	N/A ⁸	N/A
	Secondary school curriculum/material	6 teachers; 404 students	++ (pre to post)	++ (confidence in knowledge) + (interest to learn more; post only)	N/A	++ (students who saw vs. didn't see video, post only ⁹)	N/A ⁸	N/A
	Community workshops	95 adults	++ (pre to post)	NS (belief ¹⁰) + (interest to learn more; post only)	N/A	+ (post only)	N/A	N/A

Key: ++ = One or more statistically significant positive findings; + = One or more “clinically positive” findings, no test of statistical significance; - = One or more “clinically negative” findings, no test of statistical significance; NS = not statistically significant; I = intervention group; C = comparison group; N/A = Not applicable because not measured.

Notes:

¹ The numbers in this cell reflect the third pilot.

² The CHW trainings had very small Ns, variable attendance, and pre/post matching challenges, and the third training wave had no pre-test. Results are not summarized in this table but are discussed briefly (in largely qualitative terms) in the main report body, below.

³ Significant positive findings were found for selected aspects of genetics and health knowledge; pilot 1 healthy pregnancy knowledge findings were set aside due to methodological issues.

⁴ Note that methods of statistical assessment for the knowledge items differed across Howard’s pilot 1 and pilot 2, so the findings from the two pilots are not directly comparable.

⁵ Statistically significant positive outcomes were found only among certain subpopulations, within particular knowledge categories.

⁶ Change in overall knowledge score for family health history was not significant. Change in overall knowledge score for race, genetics, and health was significant.

⁷ Only limited analyses of the follow-up behavioral data had been carried out as of the time this report was being finalized. Some positive and some negative changes in both activities pledged to and activities not pledged to were identified.

⁸ Evaluation of Utah’s school-based interventions included assessment of whether students shared materials with their parents, but as this sharing was done as part of homework assignments (which were intervention components), measurement of these student behaviors has been treated in this report as part of process evaluation, not outcome evaluation.

⁹ Analysis of post-test intention (i.e., to complete family health history) was limited to students who did not complete the family health history homework assignment.

¹⁰ Belief that diet and exercise could reduce chances of getting inherited disease was essentially at ceiling at baseline and did not change significantly at follow-up.

CBWCHC was the only site that specifically targeted one gender group (i.e., women). Among the other sites, there were no specific gender-related targets, but participation by gender is worthy of examination. Utah's school-based interventions had "captive" student audiences and reached approximately equal percentages of boys and girls. Among the other interventions, recruitment efforts targeted both genders; however, rates of male participation were for the most part low. The intervention that reached the highest percentage of voluntarily participating males was Utah's Tongan community workshop; the most plausible explanation for the relatively high rate is that the workshops took place in settings (e.g., churches, senior centers) and at times in which men were already present. No site undertook a specific, tailored effort to reach out to men; such an approach might have helped to increase male participation.

With respect to outcomes, all of the sites demonstrated at least some positive, short-term changes in participants' knowledge and other behavioral determinants, such as interest in learning more about genetics and intentions to discuss family health history with family members and/or health care providers. No site documented any statistically significant negative changes in participant outcomes.

Among the common outcome study limitations across many interventions were lack of mid-term or longer-term follow-up and lack of a comparison group, which limited or precluded measurement of whether short-term changes in behavioral determinants were sustained, whether behavioral changes were achieved, and whether these changes were attributable to CGEN. These are common limitations among community-based, "real world" evaluations that have modest evaluation budgets.

Overall, the available quantitative and qualitative data suggest that all of the sites showed considerable success in making genetics more accessible, appealing, and relevant to members of underserved ethnic and racial minority communities, through the development and implementation (or deployment) of culturally and linguistically appropriate interventions and materials. A focus on the importance of lifestyle (especially diet and physical activity) for mitigating the expression of genetically linked diseases was a common theme across many of the interventions. Family health history also emerged as a common theme and appeared to help participants to personalize educational content. Together, these approaches may ultimately help foster sustained, desirable behavioral changes among the targeted participants.

Dissemination of Evaluation Findings and Solicitation of Feedback

As of the writing of this report, Phase II findings had been shared and discussed in a variety of ways. Within the CGEN team, findings were shared via phone, at in-person meetings, and through email. Each site also shared and discussed findings with its CAB and/or with other community constituents. A number of the CGEN sites also presented evaluation findings at professional conferences, and one site shared its findings at a local press conference. Overall, sharing of findings with the general public (locally or nationally) was rather limited. Two of the sites had plans to post a summary of their evaluation findings on their website; however, as of the date that this report was finalized, findings were not yet posted.

Additional Phase II Outcomes

Project outcomes among CGEN local sites, their staff, and other community partners were not measured formally in Phase II. However, a review of project documents and more informal team discussion suggested that the project did have some effects on these stakeholders. In particular, local and national CGEN team members reported gaining greater experience with CBPR; improving their ability to address issues of cultural and linguistic competence; expanding or strengthening relationships with (other) community agencies; increasing their capacity to make genetics and health information accessible to underserved and low-literacy communities; and learning how to better evaluate and disseminate their project materials and findings. Anecdotally, several team members also reported that CGEN had an impact on their own health-related behaviors. Cross-site communication was a particularly important vehicle for achieving these outcomes. In particular, CGEN team members shared educational materials, evaluation tools, and program implementation and evaluation techniques through conference calls, in-person meetings, email, and the shared online workspace that March of Dimes made available to the project team. Sites learned from each other and then selected, adapted, and applied those items that fit their needs.

In addition, community members trained by DWDC to serve as CHWs expanded their presentation and facilitation skills. Some have since gone on to work as CHWs or other health information brokers in other settings. A total of 15 graduate students in Howard's Genetic Counseling Training Program served as volunteer assistants for Howard's community workshops. In addition to helping the CGEN program, they derived valuable real-world experience interacting with community members around issues of genetics and health. Graduate student volunteers also gained evaluation-related experience by assisting with data collection activities during the workshops and by working with the local evaluator to complete the evaluation study's two-month follow-up interviews.

Collectively, over the Phase II period, these outcomes increased the capacity of the CGEN partner agencies, their staff, and their community partners to address the health-related needs of community members. This in turn has advanced the ultimate CGEN goal of decreasing health disparities.

Challenges and Lessons Learned

The CGEN team experienced a number of implementation and evaluation-related challenges, and learned many associated lessons.

Reaching the intended populations. Specific challenges with program reach included securing participation of the targeted racial/ethnic and geographic groups, given that genetics is not the most pressing or accessible issue for most people; and reaching males as well as females.

Helpful strategies to reach particular audiences included targeting "captive" student audiences, developing student materials that would simultaneously facilitate parent education, leveraging local CGEN agencies' reputations as trusted service providers to build relationships with implementation partners, and getting assistance from CAB members and/or the local March of

Dimes Chapter to identify implementation partners. Fostering positive relationships with on-the-ground partners is particularly essential when the lead agency is not itself a community-based organization. Clearly delineating responsibilities and timelines and providing stipends to partner agencies can help avoid misunderstandings and foster responsibility and commitment. Additionally, offering culturally, geographically, and age appropriate incentives (e.g., gift cards, public transportation tickets) can increase community participation in pilot implementation efforts.

Leveraging settings frequented by men may help to encourage male participation in genetics education programming. It would also be worth considering what specific health-related topics (e.g., prostate cancer), formats, or settings might be particularly appealing to males. A “male involvement” approach to genetics education might leverage lessons learned from efforts to involve males in other health prevention and promotion efforts, such as teen pregnancy prevention.

Addressing common elements of local evaluations. As was indicated above, all local evaluations had some common requirements and expectations, including IRB approval, development of logic models, implementation of both process and outcome evaluation activities, and a CBPR approach. A number of challenges arose in relation to these elements.

In particular, some miscommunication arose among project partners concerning IRB requirements, leading to Phase II delays at some sites and raising questions about the level of control that community organizations have in multilevel partnerships. Helpful strategies to address IRB challenges include stating requirements and timelines clearly, in writing, at the outset of the project and reviewing them periodically to address questions or concerns.

An additional challenge was that while sites developed logic models in Phase II, which was helpful for evaluation planning, interventions had already been developed by that time, limiting the opportunity to use logic modeling to strengthen intervention approaches. Training in logic modeling and formal theories at the outset of the project would likely have helped sites to plan programs that further leveraged existing knowledge of “what works” to change health-related behaviors. Such training could have fruitfully included local site staff and evaluators, CAB members, and (as appropriate) other local community constituents, so that each local team could have worked together to apply the concepts to their CGEN Phase I-III efforts.

Another challenge was that the abandonment of early plans to develop a common core set of cross-program outcome indicators and measures complicated efforts to “roll up” or summarize CGEN program reach and effectiveness. The diversity of intervention approaches and target populations, some cross-site disagreements over the validity of particular measures, and turnover on the national evaluation team at a crucial point in the project timeline all made establishment of common measures a daunting task. In retrospect, however, it would have been useful for the team to have made more effort—in Phase I—to agree upon and build in at least a few common cross-site measures and specific survey questions. These might have addressed selected site characteristics, participant demographic features (e.g., age, gender), and knowledge and attitudinal items.

Finally, given that CGEN was conceptualized as a CBPR project, it was expected that community involvement would be robust throughout all project phases. However, involvement of CABs or other community constituents in evaluation design, instrument development, and interpretation and dissemination of findings was fairly limited. A couple of sites experienced challenges keeping CABs or other community constituents engaged over the five-year grant period, as intervention materials were revised and planning processes were carried out. In particular, loss of interest and competing professional and personal responsibilities resulted in attrition. As various researchers have noted, involving community constituents robustly and effectively takes considerable planning and often involves lengthy timelines. Setting specific goals for community involvement, delineating all parties' responsibilities and timelines clearly up front, providing incentives, having periodic check-ins, providing needed training or support, and celebrating successes can help to keep community stakeholders engaged, even in the face of strong, competing pulls on individuals' and organizations' resources.

Developing and deploying appropriate instruments and procedures. All of the sites experienced some challenges developing and implementing evaluation instruments and procedures that would be culturally, linguistically, and literacy-level appropriate for their target audiences. A related challenge was developing instruments that collected sufficient data to validly assess outcomes without overburdening participants and consuming contact time needed for key educational activities. The majority of sites experienced instrument and/or procedural challenges during their major pilot studies that led them to stop these studies, make revisions, and undertake new pilots. Key lessons included: involve CABs or other community constituents to review instruments for cultural, linguistic, and literacy-level appropriateness; set aside time and other resources to conduct small-scale pilot-testing of instruments and procedures before deploying them in a larger-scale field test; allow sufficient time during data collection to make accommodations (e.g., reading questions aloud) for low-literacy respondents; and consider alternate or complementary methods for collecting outcome data that do not require participants to read and write (e.g., focus groups).

Additionally, all of the local CGEN evaluation studies had multiple logistical issues to address, such as how best to explain evaluation instruments and procedures to participants, how to link pre- and post-test surveys, how to document program implementation, and how to minimize missing data. Some sites experienced more challenges than others in relation to these issues. Sites were able to discuss, share, and implement a number of relevant best practices, such as ordering survey questions so that less sensitive questions preceded more sensitive questions; color-coding pre- and post-test surveys to facilitate instruction-giving and survey completion; using anonymous project code numbers and pre-prepared packets to ensure that completed pre- and post-test surveys could be matched; and, when appropriate, using trained third parties to answer participants' technical questions and/or to handle (or assist with) evaluation procedures, so that facilitators or educators could focus on intervention delivery.

Another challenge was that limited contact time with participants, and competing program vs. research needs, often made it difficult for program staff to deliver the planned intervention activities fully and consistently. In addition, for some interventions, differences among participants and among program staff's backgrounds led to variations in intervention content and delivery. Because such variations present challenges for assessing program outcomes,

documenting program delivery is an important evaluation component. Yet some interventions did not formally document program delivery; among others, documentation was extremely limited. Program delivery documentation instruments should be developed collaboratively by local evaluators and program staff. When program educators or facilitators will be documenting program delivery themselves, training should be provided on what information to capture, where, when, and how. When possible, having an external observer document program implementation can bring greater objectivity to the assessment and also alleviate additional evaluation burden on program staff, who are already occupied with intervention tasks.

Finally, in research studies involving minimal risk to human subjects, it is common to collect all of the data before conducting analyses. While this helps to ensure a robust sample size for analysis, it often precludes awareness of crucial intervention or evaluation problems until it is too late to fix them. Although it can be time-consuming (and can carry a risk of drawing invalid conclusions based on small datasets), investing in data monitoring activities up front can save time and money later, as teams can make informed decisions to stop, adjust, and re-start studies, if warranted, before full budgets and timelines have been expended.

Achieving change among participants. While genetics knowledge tended to increase overall from pre- to post-test across sites, responses did not usually reach 100% (or nearly 100%) correct for any survey item, for any population. A notable percentage of participants still appeared to be leaving workshops with misconceptions or misunderstandings. This underscores the fact that while brief educational interventions can improve knowledge, changing even basic genetic knowledge among everyone in a group is challenging, given the abstract nature of the material, different individual learning styles, and the persistence of cultural norms and beliefs about heredity and health that may be at odds with scientific principles of genetics.¹

To help address the knowledge gaps that appeared to remain even after intervention participation, two sites began providing the correct answers to the evaluation survey knowledge questions immediately following post-program data collection. Workshop facilitators also provided participants with contact information for resources that could address any further questions. More broadly, sites found that helping participants to personalize the information—e.g., by providing culturally and geographically relevant examples, encouraging documentation of family health histories, and stressing relevance of the material for one’s children and grandchildren—was a useful strategy for generating interest in genetics and intentions to engage in positive behaviors related to genetics and health.

Adhering to timelines. Phase II was originally projected to last one year. However, local sites’ Phase I activities were delayed, resulting in a late start to Phase II; and once initiated, Phase II in effect lasted for over 3.5 years. The Phase II delays were the result of the many challenges discussed above, as well as others, including project staff turnover and several sites’ unexpected need to make multiple rounds of intervention material edits, in response to Phase II feedback from community constituents. Delays to local site Phase II activities also delayed national

¹ It is also possible, in some cases, that limited literacy skills resulted in validity issues with the data. That is, although all of the sites took steps to address the needs of low-literacy evaluation participants—e.g., by reading survey questions aloud or helping participants one-on-one—it is still possible that some participants had correct knowledge but were unable to demonstrate this knowledge through the written evaluation surveys.

evaluation activities and significantly reduced the time and budget available to the CGEN team for Phase III dissemination activities.

As various researchers have noted, CBPR projects need lengthier timelines than many other types of research projects. While the original CGEN timeline was overly ambitious, it is hoped that application of the lessons highlighted here may help to inform more realistic timelines and streamline processes for future projects.

Engaging in multisite/multilevel implementation and evaluation projects. One of the benefits of multisite/multilevel projects is that they bring together parties with complementary experience and expertise that can be leveraged to generate ideas and solve problems. The challenges of such projects, however, include the difficulty of establishing common indicators and “summing up” reach and effects, as was discussed above. Other challenges include tensions and miscommunications over roles and responsibilities, and how best to capture outcomes (expected or unexpected) among partner organizations and staff.

To avoid misunderstandings and tensions over roles and responsibilities, it is essential to develop and discuss guidelines at the outset of the project, to revisit them periodically, and to revise them, as needed. Periodic phone and/or in-person meetings among the entire project team and among subgroups afford crucial opportunities for updates, discussion, and clarification. In addition, procedures and materials should be in place to debrief outgoing staff members and orient new team members, to reduce challenges that can arise in context of staff turnover.

While much attention is usually focused on evaluating individual interventions, far less attention is generally devoted to tracking and documenting key outcomes (expected or unexpected) among partner organizations, their staff, and community constituent collaborators, as a result of their participation in the multisite/multilevel project. In retrospect, a brief annual cross-site questionnaire might have helped CGEN sites to document organizational, staff, and partner outcomes more systematically. At the same time, even a short questionnaire would have added additional reporting burden to the sites, which already had numerous competing responsibilities. In short, achieving an appropriate balance between the needs of research, on the one hand, and the needs of local site practice, on the other, is a common challenge in CBPR work that has no “one size fits all” solution.

Implications for Practice, Research, and Policy

The experiences and findings of Phase II of the CGEN project have a number of important implications for practice, research, and policy.

1. In real-world projects, there will always be tensions between programmatic and research needs. Balancing these needs effectively requires open communication, close collaboration, and trust among program and research staff, as well as creativity and compromise.
2. Similarly, multisite/multilevel efforts need effective communication and meaningful collaboration to be successful. Laying out clear goals, agreeing on guiding principles, signing formal agreements, and having regular check-ins can help to avoid misunderstandings and promote strong working relationships. Up-front and ongoing capacity-building on key

approaches and procedures is also important, particularly in the context of high project staff turnover. A coordination and technical assistance center that is dedicated to implementing these activities can serve as both the "glue" that keeps partners together and the "oil" that keeps the project moving smoothly forward. However, in CBPR projects, it is also essential that all partners feel empowered and remain actively involved in decision-making. Balancing the imperatives of moving forward—but not leaving anyone out or leaving anyone behind—is one of the biggest challenges of CBPR work.

3. CBPR projects take “bottom up” approaches, in which needs, assets, goals, and strategies emerge from and are developed by the community; however, research tools and frameworks (such as logic modeling and formal behavioral and learning theories) can still be fruitfully applied. Up-front capacity-building around both research- and community-driven tools and frameworks is essential so that all stakeholders have a common language and shared understanding of processes.
4. It is also essential to involve community constituents actively throughout all phase on a CBPR project, from development and planning to implementation and evaluation to dissemination and sustainability. This involvement may take different forms, but most require that considerable time be built in for the iterative processes involved. Defining roles, setting realistic timelines, celebrating milestone successes, and providing appropriate incentives can help to sustain community interest and participation, even when timelines are lengthy.
5. For their part, community constituents must maintain flexibility and willingness to adapt their plans (e.g., narrowing goals, bringing on additional experts to provide input on technical issues), if it becomes clear that their original aims were not realistic or that their processes have not yielded the intended progress.
6. Even when goals, approaches, and populations differ across interventions in a multisite project, it may still be feasible and desirable to develop a small set of common indicators, measures, and instruments for both individual site interventions and partner-level outcomes, so that it is possible to document and sum up overall project impact.
7. Obtaining community input to evaluation instruments and protocols and then conducting a small-scale pilot requires time and resources but can increase the likelihood that larger-scale evaluation will run smoothly. Monitoring evaluation activities and findings in real time can help to ensure that unanticipated problems are identified and addressed as rapidly as possible.
8. Beliefs about heredity and health are often linked to deeply held cultural beliefs. Moreover, genetic science is a discipline that many people consider to be far removed from their everyday life concerns. These factors can make it challenging to increase even basic knowledge of certain genetics concepts. Yet, it is possible to educate people about genetics—and the interrelationships among genetics, environment, behavior, and health—in ways that make the material relevant and accessible. Across cultural and linguistic groups, collection of family health history has emerged as a key strategy for generating interest in genetics and health, and helping community members to personalize and act on key messages about how they can reduce their risk (and their family members’ risk) of developing genetically-linked diseases. Genetics education interventions and materials should include images and examples

that are culturally, linguistically, geographically, and literacy-level appropriate and highly salient to the target audience, to emphasize the relevance of the material to their lives.

9. Reaching men with genetics education programming may require targeted strategies, such as leveraging existing settings or activities frequented by men and addressing specific topics of particular interest and relevance to men. Best practices for involving males in other health issues (e.g., teen pregnancy prevention, family planning) might be fruitfully leveraged in genetics education programming.
10. One of the goals of CGEN has been to increase consultation with health care providers about genetics and health. Phase II data suggest that some CGEN interventions increased intentions among participants to engage in this behavior. However, as an audience member at the 2009 APHA Annual Meeting CGEN presentation session asked, do health care providers (such as primary care physicians, nurse practitioners, and obstetricians) have the information and skills to respond appropriately to community members' overtures? Educational programming and related resources for practicing clinicians and for clinicians-in-training need to build their knowledge of genetics and health, as well as their skills to interact appropriately about these topics with persons of diverse cultural and linguistic backgrounds and literacy levels. Increasing genetic literacy and cultural competence among health care providers is an essential complement to ongoing community-focused genetics education efforts.

I. Introduction

In 2005, the U.S. Health Resources and Services Administration (HRSA) funded a five-year cooperative agreement with the March of Dimes called the Community Genetics Education Network (CGEN) project. The overall goal of the CGEN project was to increase the genetic literacy of African Americans, Latinos, Asian Americans, and Pacific Islanders, in order to promote:

- Informed health decision-making;
- Consultation with family and health care providers about genetics and health;
- Use of genetics services among high-risk populations; and
- Adoption of lifestyle changes to reduce genetic-based health risks.

The CGEN project has applied principles of community-based participatory research (CBPR) to develop, plan, implement, evaluate, and disseminate culturally and linguistically appropriate genetics education interventions and materials for low-literacy populations of diverse cultural backgrounds. CBPR has been increasingly recognized as an effective means to help people focus energy and mobilize resources to solve local health, environmental, and economic problems (Wallerstein & Duran, 2003). In particular, in recent years, many public health initiatives have coalesced around the notion of reducing or eliminating health disparities in underserved communities, while promoting broader community and social change (U.S. DHHS, 2000); however, traditional “outside expert” approaches to investigating issues and implementing programs that address community problems have proven to be inadequate. Disillusionment with the disappointing outcomes of such approaches has been accompanied by increasing community demands for truly collaborative research that addresses locally-identified issues. In public health, social work, and related fields, CBPR has been increasingly acknowledged as the term that best captures this paradigm. Building on the work of a number of researchers (Green et al., 1995; Israel et al., 1998), the W.K. Kellogg Foundation’s Community Health Scholars Program (2001; cited in Minkler & Wallerstein, 2003: 4) proposed that:

Community based participatory research in health is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health....

The “action for social change” in the CGEN project has been the development, planning, implementation, evaluation, and dissemination of programs that will ultimately help the target communities.

Four CGEN sites engaged in these processes with selected communities. The sites and their respective communities are as follows:

1. The Charles B. Wang Community Health Center (**CBWCHC**) in New York City developed and implemented Chinese-language genetics education workshops for at-risk prenatal patients, prior to their meeting with a genetic counselor. CBWCHC also produced five Chinese/English bilingual brochures and two Korean/English bilingual brochures on topics related to genetics and health.

2. The Dominican Women’s Development Center (**DWDC**) in the Washington Heights/Inwood section of New York City developed and implemented a bilingual (Spanish/English) genetics education curriculum for Community Health Workers (CHWs) or *promotores/as de salud* (health promoters). The CHWs in turn used the project’s bilingual materials to deliver genetics education workshops to community members.
3. The National Human Genome Center and Department of Community and Family Medicine at Howard University (**Howard**) in Washington, DC developed two interactive booklets, “Race, Genetics and Health” and “Planning for a Healthy Future: The Importance of Family Health History” and used them in community workshops with African Americans. They also created an associated toll-free informational number and website.
4. The Genetic Science Learning Center at the University of Utah, in partnership with the Utah Department of Health Chronic Disease Genomics Program (**Utah**), Salt Lake City, developed and implemented bilingual genetics education curricula and materials for fifth grade students (Spanish/English), secondary school students (Spanish/English), and Tongan adults (Tongan/English). They also produced related educational materials for general audiences.

The four sites that were chosen to participate in CGEN represented—and/or had access to—underserved racial and ethnic minority group populations, had completed genetics needs and assets assessments in the target communities prior to CGEN project initiation, and had track records of implementing community genetics education activities. All sites had a local project evaluator to document and evaluate project activities. A national evaluation team based at the Midwest Latino Health Research, Training and Policy Center, University of Illinois at Chicago, provided evaluation guidance and oversight.

Throughout the CGEN project, the March of Dimes served as a coordinating center. In this capacity, the organization provided project management, technical assistance, quality assurance, and general guidance, and it worked to foster and enhance collaboration among the CGEN project partners as well as promote relationships with other organizations. In particular, March of Dimes supplied the sites with information on CBPR to help them work with their respective geographic and racial/ethnic communities. Sites were also provided with technical assistance, either by March of Dimes staff or by outside experts, on how to develop materials for low-literacy audiences, carry out translations, sustain and disseminate their interventions and materials, and publish in peer-reviewed journals. In addition, March of Dimes implemented a system of regular conference calls, reports, and in-person meetings, and encouraged project partners to contact each other directly to discuss relevant issues. The organization also hosted a password-protected web-based workspace that allowed participants to communicate and share documents.

The CGEN project was implemented in several (overlapping) phases:

- ***Phase I - Partnership formation, program planning, and development.*** This phase began in June 2005. For many local interventions, it was completed by late 2007, but for some it continued through 2009.

- ***Phase II - Community awareness and education, including implementation and evaluation of culturally and linguistically appropriate genetics education interventions.*** This phase began as early as December 2006 or the first quarter of 2007 for several interventions, and for a number of interventions Phase II activities continued into the first half of 2010. For most sites, an initial implementation/evaluation pilot study was followed by a period of revisions to procedures and materials and a second pilot study.
- ***Phase III – Dissemination of interventions, educational materials, and best practices to other sites and the broader field, and institutionalization/sustainability of promising practices in CGEN sites.*** For one intervention, this began in late 2007. However, for most interventions, dissemination and sustainability efforts did not become a focus until 2010.

This national evaluation report addresses the processes and findings of the CGEN project's ***Phase II***, implementation and evaluation of culturally and linguistically appropriate genetics education interventions in the four community sites. The logic model (version of 6/30/08) for this project phase is shown in Figure 1, below.² In brief, inputs to Phase II included the curricula, materials, and tools and learnings produced in Phase I, the local and national project partners, HRSA funding, selected theoretical frameworks (such as CBPR, among others), and additional resources available to the team. These inputs were brought to bear to implement (or deploy) and evaluate culturally and linguistically appropriate interventions and materials, which were hypothesized to increase genetic and health knowledge and literacy, and positively impact other behavioral determinants (e.g., self-efficacy, attitudes, and intentions), over the short-term. Positive short-term effects on behavioral determinants were in turn hypothesized to lead to positive mid-term effects on behaviors, including increased information-seeking around genetics and related health issues; increased discussion with family, broader social networks, and health care providers about genetics and health; improved quality of patient-provider communication in genetics-related encounters; and increased healthy lifestyle choices (e.g., diet, physical activity) relevant to genetic conditions. In addition, evaluation of the CGEN interventions and the resultant learning were hypothesized to contribute to more efficient and effective genetics education programming. Ultimately, the desired outcome of the project was decreased disparities in morbidity and mortality related to genetic and environmental conditions, among underserved populations. While this outcome has not been measured in the CGEN project, it is the overarching goal that drove the partners' work.

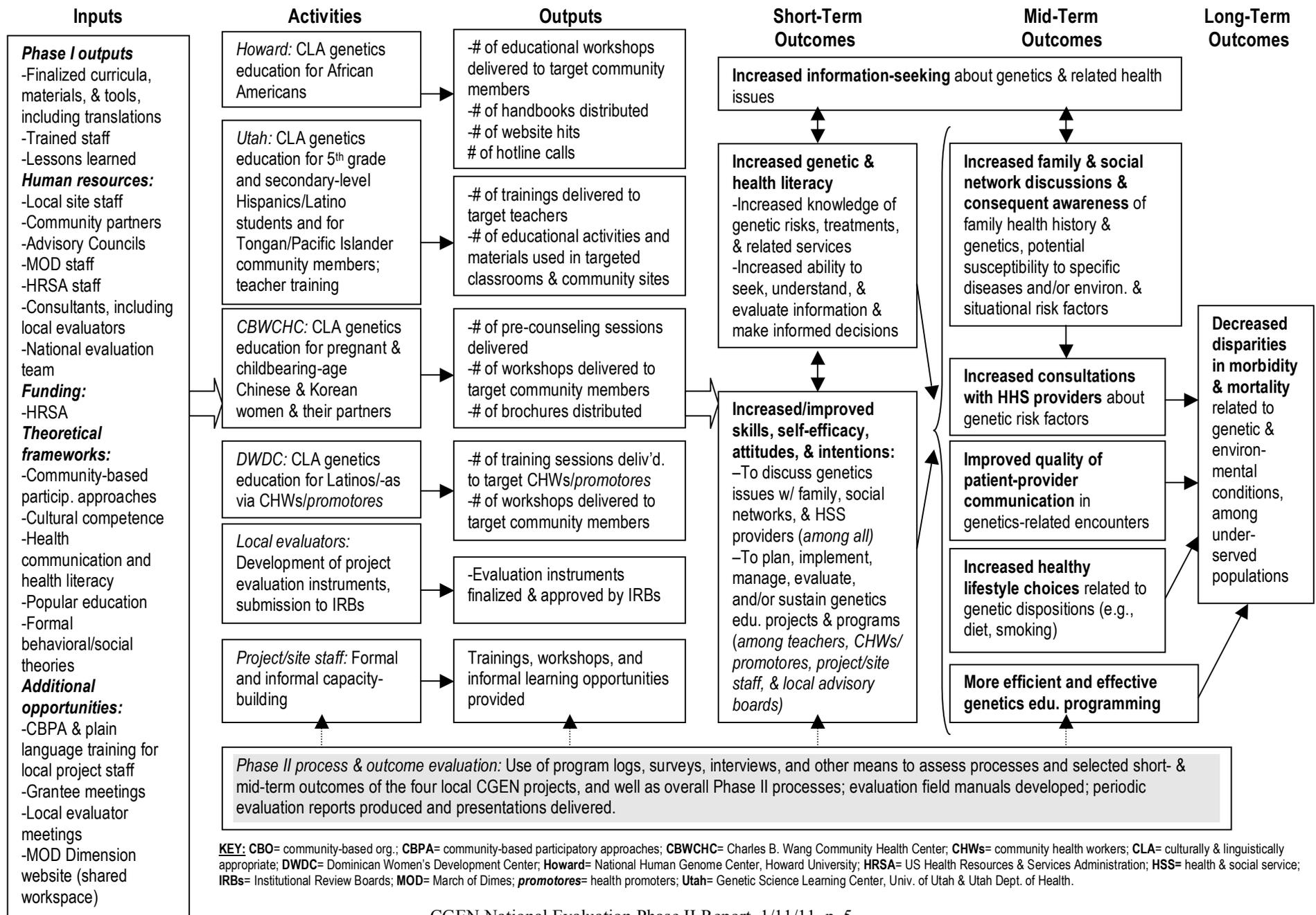
This report summarizes the Phase II methods, outputs, and outcomes across sites, with the goal of identifying overarching challenges, lessons learned, and best practice implications. Specifically, Section II summarizes the methodologies used in the development of this report, Section III provides an overview of the local site interventions, Section IV briefly describes the roles of the various project partners in Phase II, and Section V summarizes common elements of the local evaluations and provides an overview of the specific local evaluation designs and methods. Section VI then summarizes and discusses the local evaluation findings, and Section VII addresses how these findings have (as of the writing of this report) been disseminated and

² A *logic model* is a table or diagram that shows the links among a program or project's inputs (resources), activities, outputs, and outcomes. It is a visual representation of a program or project's theory of change (Frechtling, 2007; W.K. Kellogg Foundation, 2004). See also section V.A.2.

discussed both within and outside the project team. Section VIII briefly discusses additional Phase II outcomes among project staff and local sites. Finally, Section IX details implementation and evaluation challenges and lessons learned from the Phase II project, and Section X summarizes best practice implications for practice, research, and policy, based on the Phase II project experiences.

Figure 1. Logic Model for Community Genetics Education Network (CGEN) Project Phase II: Community Awareness & Education

Overall Phase II goal: To implement and validate culturally & linguistically appropriate (CLA) genetics education programs



II. Report Methodology

This report provides a descriptive synthesis and a largely qualitative, thematic analysis—executed “by hand” (as opposed to by means of qualitative analysis software)—of Phase II activities, outcomes, and learnings. It draws on a number of data sources, including:

- Local project coordinator and local evaluator quarterly reports
- Local Phase II evaluation reports and field manuals
- National evaluation semi-annual reports
- Evaluator call and CGEN team quarterly conference call minutes
- CGEN team in-person meeting minutes
- CGEN American Public Health Association (APHA) Annual Meeting slidesets
- Other CGEN historical documents

Local evaluators’ Phase II evaluation reports and field manuals were a particularly rich source of information for this report. This report also reflects ongoing discussions among team members—often but not always captured in formal meeting minutes—about project progress, challenges, and strategies. As such, it represents collective institutional memory and insight that grew over time.

The objective of the present report is not to provide exhaustive detail on the implementation practices or evaluation methods or findings of each local intervention. Such information is available in local sites’ quarterly reports, Phase II reports, and field manuals. Instead, the present report focuses on summarizing methods and findings and deriving overall challenges, strategies, and best practice implications that have emerged from the review of local and national Phase II efforts. Officially, the data in this report cover the period January 2007-June 2010. However, in some cases information from shortly before or after this period has been included, in order to provide a more comprehensive picture of Phase II challenges and accomplishments.

III. Overview of Local Interventions

Each of the four CGEN sites developed interventions and materials that targeted a specific population or populations that it represented or to which it had access. Specifically, in Phase I of the project, each site collaborated with a community advisory board (CAB) and (as appropriate) other community constituents and/or outside consultants to develop interventions and materials that would be culturally, linguistically, and health literacy-appropriate for the designated population(s). Each site’s target population(s), intervention approaches, and settings are summarized in Table 1 and discussed briefly below.

Table 1. Overview of Local Interventions

Site Lead(s)	Phase II Target Population(s)	Intervention Approach ¹ & Setting
Charles B. Wang Community Health Center (CBWCHC), New York City	• Chinese American, largely foreign-born, at-risk prenatal patients attending CBWCHC clinics in Chinatown and Flushing, New York City	• 20-30 minute clinic-based genetics education workshop prior to patient’s meeting with genetic counselor
	• Chinese and Korean foreign-born adults in the New York metropolitan area	• Educational brochures
Dominican Women’s Development Center (DWDC), New York City	• Latino/a adults (largely Spanish-speaking Dominican immigrants) in the Washington Heights/Inwood section of New York City	• Multi-session training of community health workers (CHWs) • Two-module (about 2 hours total) genetics and health workshop in community settings
Howard University (Howard), Washington, DC	• African American adults in selected (lower socioeconomic) wards in Washington, DC	• 45-minute genetics and health workshop (including use of interactive booklets and trigger video) in community settings • Website • Toll-free information line
University of Utah Genetic Science Learning Center (GSLC) and the Utah Dept. of Health (Utah), Salt Lake City, UT	• 5th grade and secondary school Hispanic/Latino students ² in Salt Lake City and Ogden, UT school districts	• School curricula and bilingual educational materials (including take-home materials) • Secondary school materials also included a video
	• Tongan/Pacific Islander community members ³ in Salt Lake City, UT	• 60-90 minute genetics and health workshops in community settings

Notes:

¹ Intervention lengths as listed in the table do not include time required for evaluation activities.

² Students’ families were the secondary target of the school-based interventions, as it was hoped that students would share materials with parents/family through take home activities.

³ The original intent was to develop a curriculum that would be appropriate for Tongans and other Pacific Islanders, but ultimately the curriculum that was developed was most appropriate for a Tongan audience (see Section III.D).

III.A. CBWCHC

CBWCHC in New York City developed a pre-counseling workshop for pregnant, foreign-born, Chinese American patients who are identified to be at risk for negative birth outcomes due to thalassemia, abnormal triple screen results, and/or advanced maternal age. The short-term objectives of the workshop are to increase basic knowledge of genetics, the role of genetics in health, and genetic disorders that are particularly common in Asian American communities; increase awareness about genetic counseling and testing services as part of prenatal care and family planning; increase self-efficacy and intentions to discuss concerns regarding genetics and family health history with a genetic counselor or other health care provider; and improve quality of communication between the genetic counselor and patient and optimize the counselor's ability to enable the patient to make informed health-related decisions. The pre-counseling workshop was specifically developed for use with patients who are recent immigrants and have low acculturation levels, limited English proficiency, and low health literacy.

The workshop consists of a one-on-one 20-30 minute genetics education session for pregnant women (and their partners, if they wish to attend) who are referred for genetic counseling because of risks related to thalassemia, abnormal triple screen results, and/or advanced maternal age. The patient (and partner, if desired) attends the session immediately prior to her scheduled appointment with the genetic counselor. The session is conducted in Chinese by a trained health educator. Three versions of the curriculum are available; all provide basic "genetics 101" education, as well as discussion of the purpose and meaning of genetic testing and counseling, patient risk factors, and specific testing procedures like amniocentesis and ultrasound. Each curriculum also provides tailored content for the respective risk group (thalassemia, abnormal triple screen, advanced maternal age). Patients leave the workshop with relevant bilingual (Chinese/English) take-home brochures (see also below).

CBWCHC also developed a set of five culturally and linguistically appropriate bilingual educational brochures. Each brochure concerns one of the following topics: genetic counseling and testing; thalassemia; amniocentesis; maternal serum-triple screen; and family health history. The content was first developed in English by the project team. It was evaluated for medical accuracy by CBWCHC's health care providers, and for cultural and linguistic appropriateness by CBWCHC's bilingual/bicultural health educators. Then the content was translated into Chinese by CBWCHC's in-house translators. The translation was reviewed for linguistic accuracy and cultural relevancy by several reviewers (CBWCHC's health educators; Women's Health Department staff; the Women's Health Advisory Committee, which was CBWCHC's CAB; the project team; and health center volunteers, all of whom are native Chinese speakers who know the population). The brochures on genetic counseling and testing and amniocentesis were also adapted for the Korean community and are available in Korean/English. Written in plain language and with as little medical terminology as possible, the brochures explain common genetic terms and concepts that the patient should be aware of when considering prenatal genetic screening or genetic counseling, and they explain the benefits and risks of particular genetic tests. Through the brochures, patients, their family members, and other community members can gain knowledge and consider cultural barriers and stigma related to genetics and health. As a result, patients and community members can gain self-efficacy to access and use genetic counseling and testing services.

III.B. DWDC

DWDC developed a two-module genetics education community workshop for Latino/a (largely Dominican immigrant) adults in the Washington Heights/Inwood neighborhood of New York City. The workshop is designed to be delivered in community settings, such as social service agencies, churches, and homes. The workshop's principal short-term objectives are to increase knowledge of genetics and the effects of the environment on inherited conditions; increase awareness of genetic conditions particularly relevant to Latinos/as; increase awareness of and access to community services related to genetics and health; and increase self-efficacy and intentions to discuss genetics and family health history with service providers and family members. DWDC also developed a training for community health workers (CHWs) to empower them to deliver the genetics education workshop in community settings.

The curriculum and materials to be used for the CHW training and community workshops evolved considerably throughout the CGEN project. Initially, a 12-module curriculum was developed in Spanish by an Argentinean geneticist. The modules were translated into English by a local translator, but the team found problems with the translation and the reading level (sixteenth grade) of the material. A consultant was hired to adjust the English material to an eighth grade reading level. In addition, the English version of the curriculum was narrowed to six modules, reviewed for scientific accuracy by a medical consultant, reviewed for English language accuracy, and eventually translated back into Spanish. However, at a CHW training in February 2009, CHWs provided feedback to project staff that there was just too much information in the curriculum to absorb in the CHW training sessions and teach effectively in brief community workshops. The team responded by using content from the six-module curriculum to develop a streamlined, two-module curriculum that includes: (a) a participant workbook (available in Spanish and English versions); (b) a flipchart for each module that includes culturally appropriate images and text for participants to view on one side of each page (available in English and Spanish versions), and bilingual talking points and notes for the CHW on the other; and (c) an associated CHW training guide (available in English and Spanish versions). All of the materials have images and examples that are culturally appropriate for the Washington Heights/Inwood Latino/a community.

The first workshop module, "Latino/a Families: How to Improve Your Health and the Health of Your Community", has a delivery time of approximately 1.25 hours, exclusive of evaluation activities). This module covers heredity and basic genetics concepts, the most common genetic conditions affecting the Latino/a community, the roles that the environment and lifestyle play in the expression of inherited diseases, how to complete a family health history, and where to find local genetic counseling services and resources. The second module, "How to Have a Healthy Pregnancy," has a delivery time of approximately 45 minutes, exclusive of evaluation activities. It covers birth defects and factors that increase the chance of having a baby with a birth defect, and provides information on the different stages of pregnancy and how to increase the chance of having a healthy baby. The second module is intended to be presented as an adjunct to the first, and not as a stand-alone workshop. Both modules include didactic presentation elements and interactive group activities. Review by a series of expert consultants, DWDC CGEN staff, and the CHWs helped to ensure that the final community workshop and CHW training materials were scientifically accurate, as well as appropriate for the cultural and language background,

literacy level, and health literacy level of the target audiences. All the materials are available on the DWDC's website (<http://dwdc.org/HGenetic.html>).

III.C. Howard

Howard developed a genetics education community workshop for African American adults in selected (lower socioeconomic) wards in Washington, DC. The principal short-term objectives of the workshop are to increase knowledge and literacy around family health history concepts and race, genetics, and health issues; increase awareness of the importance of genetics and family health history issues; increase skills to collect family health history information; and increase motivation to seek further information on topics related to genetics and family health history. Designed to last 45 minutes, exclusive of evaluation procedures, the workshop comprises two main topics: family health history (FHH); and race, genetics, and health (RGH). A PowerPoint presentation provides didactic content, and two booklets (one on FHH, one on RGH) are the source of interactive activities and take-home materials. A video-based public service announcement on FHH, created by the Howard CGEN Project, is also shown as a trigger for discussion. Close to the end of the workshop, participants are asked to sign a pledge form in which they commit to engaging in one health-related activity during the next two months: collecting family health history, engaging in positive lifestyle choices related to diet, or engaging in positive lifestyle choices related to physical activity.³

The community workshops are designed for implementation in diverse community settings (e.g., community centers, churches). The Howard CGEN Project coordinator served as the workshop facilitator in the Phase II pilot study. She was assisted by graduate student volunteers (one assistant to every ten participants) from the Genetic Counseling Training Program at Howard University. They were encouraged to respond to any technical questions posed by the workshop participants.

Howard also developed and deployed two additional resources targeted toward African Americans but accessible to a broader audience—a website and a toll-free number—to support increased literacy and knowledge of genetics, increased awareness of the importance of genetics and family health history issues, and (in the case of the toll-free number) increased consultation with health and human service providers on genetics and family health history. The website (www.myfamilies.org), which is part of Howard's National Human Genome Center site, contains didactic information (tailored for an eighth grade reading level), resources, and links on family health history and on how race, genetics, and the environment may affect a person's health. The booklets used in Howard's community workshops are also made available through the website. In addition, website users have the option to join a Howard CGEN mailing list. The toll-free number has an outgoing message that asks the caller to leave a message and refers the caller to the website. The Howard CGEN Project Coordinator returns messages by the next business day. In some cases, she may direct the caller to an expert at the Howard University National Human Genome Center or Howard University Hospital who would be better able to answer the caller's question.

³ The final version of the workshop (Howard's "pilot 2") offered these three pledge options. An earlier version of the workshop (Howard's "pilot 1") offered a longer list of choices.

Howard's CGEN project was based on several formal theories: Theory for Individual Change or Empowerment Model (King, 1999), Health Belief Model (NCI, 2005), and Stages of Change (Transtheoretical) Model (NCI, 2005; Prochaska & DiClemente, 1983). With respect to intervention approach and content, the Theory for Individual Change or Empowerment Model is most relevant. It asserts that empowerment should increase problem solving in a participatory fashion, and should enable participants to understand the personal, social, economic, and political forces in their lives in order to take action to improve their situations (King, 1999). Howard's CGEN interventions seek to empower African American community members to increase their knowledge, thus enabling them to better understand the personal, social, economic, and political dynamics related to family health history and race, genetics, and health. This knowledge can lead participants to take action and problem-solve to improve their health status.

III.D. Utah

The University of Utah Genetic Science Learning Center (GSLC) and the Utah Department of Health developed culturally appropriate bilingual (Spanish/English) genetics education materials for Hispanic/Latino students in grade five and secondary school, and for their families. Specifically, the fifth-grade materials focus on genetic traits and the difference between inherited traits and learned traits or traditions. Their principal short-term objectives are to increase student knowledge of basic genetics, increase student interest to learn more about genetics, promote sharing of information about genetics with family members, and generate an intention among teachers to use the materials with other classes. The materials comprise five classroom activities and three take-home family activities that may be used as a single curriculum (presented over a one- to five-week period) or as stand-alone activities. The materials meet selected U.S. National Science Education Standards (grades 5-8; NRC, 1996), American Association for the Advancement of Science Benchmarks for Science Literacy (grades 3-5; AAAS, 1993), and Utah Elementary Science Core Curriculum, Fifth Grade standards (Utah State Office of Education, 2002).

Utah also developed culturally appropriate bilingual (Spanish/English) materials for secondary school students. Intended for use in biology or health classes, the materials address how genetics and lifestyle choices affect risk for developing common chronic diseases. Their principal short-term objectives are to increase student knowledge of basic genetics, increase student interest to learn more about genetics, promote sharing of information about genetics with family members, promote the collection of family health history information, and generate an intention among teachers to use the materials with other classes. The materials comprise four classroom activities and a take-home family health history activity. In addition, a short bilingual video introduces students to the various topics covered. The classroom activities require between 1.5 to 2.5 class periods to implement, plus an additional week for the students to collect their family health histories. The materials address selected standards in the Utah Secondary Health Education Core Curriculum (Utah State Office of Education, 2009), as well as selected U.S. National Science Education Standards (NRC, 1996), American Association for the Advancement of Science Benchmarks for Science Literacy (AAAS, 1993), and National Health Education Standards (Joint Committee on National Health Education Standards, 2007).

Additionally, the GSLC, in collaboration with the National Tongan American Society (NTAS), developed a related 60-90 minute, single-session community workshop on basic principles of inheritance and family health history, by adapting selected materials developed for the Hispanic/Latino students. The participant materials were made available in a bilingual (Tongan/English) format. Originally, the curriculum was going to target adult members of the Tongan and other Pacific Islander communities. The images and examples used in the materials are indeed appropriate for this broad audience (see below); however, the project's community advisory board (CAB) had only one non-Tongan member (i.e., a Samoan), and the NTAS Director and the CAB ultimately translated the materials into Tongan only. (Additionally, nearly all pilot study participants were Tongan—see Section VI.D.3, below.)

The principal short-term objectives of the community workshop are to increase knowledge of and interest in basic genetics, and increase intentions to share information about genetics with family members, collect family health history information, and make lifestyle changes to reduce risk of diseases that have both genetic and lifestyle influences. The workshop includes three main activities on inherited traits and related health risk issues. In addition, a fourth activity on family health history is explained, and participants are encouraged to use the materials to collect their own family health histories after the session. The workshop is intended to be taught in churches, senior centers, and other community contexts.

Utah's CGEN interventions are all based on standard K-12 science education approaches, including research-based education principles and kinesthetic learning principles (Marzano et al., 2001). In developing the interventions, Utah used CABs made up of members of the target racial/ethnic groups (i.e., Hispanic/Latino; Tongan/Pacific Islander) to review and adapt genetics education materials previously developed by the GSLC in collaboration with teachers, so that they would be culturally, linguistically, and literacy-level appropriate. For example, in addition to adapting previously-developed materials, the Hispanic/Latino CAB developed the ideas for the fifth grade take-home family activities, recommended developing the bilingual movie for the secondary-level materials, and reviewed the translations for all materials. For the Tongan/Pacific Islander community workshops, Tongan translations were both carried out and reviewed by CAB members. In addition, a photo-shoot with Pacific Islander community members provided appropriate visuals; references to healthy and unhealthy foods were tailored to reflect typical Tongan dishes; and diabetes was made the focus of discussions about disease because of its prevalence in the community.

Utah's English/Spanish school-based materials are available at <http://teach.genetics.utah.edu>. The Tongan materials will be made available at <http://learn.genetics.utah.edu/content/begin/traits/activities/>.⁴

⁴ During the Phase II period, in response to requests from diverse groups to use the Utah materials, Utah adapted the school-based materials so that they would be appropriate for use with general (all-age) audiences (see <http://learn.genetics.utah.edu/content/begin/traits/activities/>). The materials have been used in diverse contexts, such as health fairs, a museum exhibit, open houses, and other community events. The materials also have been used in additional workshops with African American, African refugee, Chinese, Hispanic/Latino and Native American community groups, with support from a contract with the National Institutes of Health (NIH) National Human Genome Research Institute. Since they were not evaluated under the Phase II CGEN Project, the general audience materials are not discussed in detail in this report.

IV. Partner Roles in Phase II

The CGEN partners played diverse but complementary roles in Phase II implementation and evaluation activities. These roles are summarized briefly below. Importantly, the sense of a “CGEN community” increased among the partners during Phase II. This community provided support to the partners and promoted cross-site learning.

IV.A. Site Staff

The local project coordinators had lead responsibility for ensuring that the interventions and materials that their teams had developed in Phase I were implemented (or deployed) successfully in Phase II. Beyond this overarching responsibility, their specific tasks varied across sites and interventions. In particular, for some interventions, project coordinators engaged in direct outreach activities to recruit intervention participants. For other interventions, project coordinators made arrangements with intervention host sites that in turn recruited (or had access to “captive audiences” of) intervention participants. In some instances, local project coordinators delivered interventions directly to community members; in other cases, project coordinators trained or otherwise prepared community partners (e.g., teachers, CHWs, or community leaders) to deliver the interventions. Additionally, project coordinators and/or other program staff often had a lead or auxiliary role in evaluation data collection efforts. In all sites, the project coordinator collaborated actively with the local evaluator to ensure that planned evaluation activities would occur in conjunction with intervention implementation. Project coordinators submitted quarterly reports on their projects, participated in quarterly conference calls and annual in-person meetings, and also reviewed and provided feedback on local and national evaluation reports. In addition, during Phase II they each had lead responsibility for their site’s Phase III (dissemination and sustainability) planning efforts.

There was considerable turnover among local project coordinators during the Phase II reporting period, as is common for community-based projects. In particular:

- DWDC’s project coordinator through February 2008 was Ms. Anadel Nicasio. She left DWDC and was replaced by Ms. Claudia De la Cruz.
- CBWCHC’s project coordinator through spring 2006 was Ms. Deborah Hong. Ms. Mala Shah then served as coordinator through early 2007, when Ms. Hong returned. Ms. Sandra Tanamugsukbovon became coordinator in fall 2008; she was replaced by Ms. Christine Chan in summer 2009. Ms. Chan left in summer 2010 and was replaced by Ms. Shalini Vora, who was the coordinator as of the writing of this report.
- Howard’s project coordinator through May 2008 was Ms. Valerie Robinson Hill. When she left her position, she was replaced by Ms. Finie Hunter (later Ms. Finie Hunter-Richardson).
- Utah’s GSLC project coordinator was always Dr. Louisa Stark. Two staff from the Utah Department of Health Chronic Disease Genomics Program (UDOH CDGP) worked closely with the GSLC through the end of 2008, when the UDOH Genomics Program was discontinued due to a lack of funding.

IV.B. Local Evaluators

Each CGEN site had a local evaluator who worked with the site throughout all phases of the CGEN project. In particular:

- DWDC partnered with New York City-based consultant Mr. Jesus Sanchez, who had been their local evaluator on the earlier HRSA-funded GENE Project⁵, a precursor to CGEN.
- CBWCHC initially partnered with Mr. Sanchez as their local evaluator as well. However, in 2008, part way into their Phase II activities, an internal reassignment of the CGEN project from “demonstration project” status to “research” status led CBWCHC to bring the evaluation in-house to their Research & Evaluation Unit, led by Dr. Shao-Chee Sim, who became the project’s lead local evaluator.
- Howard’s initial local evaluator was Dr. Johnny Daniel (a faculty member in the Department of Sociology and Anthropology at Howard), but in the first half of 2007 he withdrew from the project. Howard then partnered with Green Consulting Company, whose Principal, Dr. Rodney Green, is the Executive Director of Howard’s Center for Urban Progress. Green Consulting evaluator Dr. Jo-Anne Manswell Butty became the lead local evaluator for the Howard project.
- Utah partnered with Bach Harrison, LLC, a survey research and evaluation firm based in Salt Lake City, for their local evaluation. Dr. Stacy Eddings served as the lead local evaluator.

The local evaluators were charged with collaborating with the local project coordinators and (as appropriate) other local constituents to plan and implement process and outcome evaluation studies and report on the findings. Throughout the project, the local evaluators had ultimate responsibility for the integrity of local evaluation processes and findings. They were required to submit quarterly progress reports to the March of Dimes and the national evaluation team, to prepare evaluation field manuals and Phase II reports, and to participate in periodic evaluation team conference calls, all-CGEN quarterly conference calls, and annual in-person meetings. They were also involved in disseminating evaluation findings to a variety of audiences, including CABs, other community constituents, the overall CGEN team, and the broader field. Apart from these common responsibilities, the local evaluators were afforded considerable latitude to develop methodologies and tools that would be appropriate for their respective sites’ interventions and population(s).

IV.C. National Evaluators

The CGEN national evaluation team was based at the University of Illinois at Chicago (UIC) Midwest Latino Health Research, Training & Policy Center (Midwest Latino Center). Their primary responsibilities during Phase II were to:

- Maintain regular communication with local evaluators through periodic conference calls and email.

⁵ The GENE Project was a five-year program funded by HRSA to investigate the genetics education needs of underserved, minority communities. March of Dimes and its national partners, Genetic Alliance and Family Voices, worked with two community partners (one of which was DWDC) to determine the cultural and linguistic needs of the respective communities in the area of genetics education and develop action plans to address those needs.

- Provide technical assistance and support to local evaluators (e.g., concerning logic modeling, instrument development, data collection and analysis methods, interpretation of findings, reporting formats, etc.) for their ongoing Phase II activities.
- Provide review and oversight for local evaluator deliverables.
- Ensure that required IRB approvals were in place and provide IRB services through UIC for sites that did not have their own IRB (i.e., DWDC, CBWCHC).
- Help the team to prepare for and engage in Phase III (dissemination and sustainability) activities, by leading development of an overall Phase III logic model, providing input to Phase III segments at the annual CGEN in-person meetings, reviewing CGEN presentation materials, and providing input to the design of program replication toolkits.
- Make an APHA presentation on cross-site Phase II methods and findings.
- Keep the entire CGEN project team up-to-date on national evaluation activities during quarterly conference calls and via semi-annual reports.
- Produce a Phase II national evaluation report (this document) and associated manuscript.

The national evaluation team originally comprised Dr. Aida Giachello, Founder and Director of the Midwest Latino Center, and Dr. Robin Bates, Director of Evaluation and Research at the Midwest Latino Center. Dr. Bates left the project in August 2007, and Dr. Julie Solomon of J. Solomon Consulting, LLC joined the national evaluation team in December 2007. Mr. Jose Arrom, Dissemination and Research Development Specialist at the Midwest Latino Center, also joined the national evaluation team at that time. Mr. Arrom had primary responsibility for UIC IRB approval efforts.

IV.D. March of Dimes

In Phase II the March of Dimes continued to serve as the project's coordinating center and to provide project management, technical assistance, quality assurance, and general guidance. Dr. Diane Ashton continued to serve as the project's Principal Investigator, and Ms. Diane Gross continued to serve as Project Director. Overall, March of Dimes National Office staff's primary Phase II responsibilities were to:

- Provide technical assistance to help sites address implementation challenges.
- Participate in evaluation conference calls and provide feedback concerning evaluation challenges and solutions.
- Organize all-CGEN annual in-person meetings and quarterly conference calls.
- Review and provide feedback on project coordinators' quarterly reports and local and national evaluators' deliverables (e.g., evaluation instruments, protocols, and reports).
- Review program materials in light of evaluation findings and assist with revising materials and protocols, as appropriate.
- Organize a 2009 APHA panel presentation on Phase II findings and review all presentations.
- Provide a toll-free conference line and an online workspace for all CGEN partners to share documents, schedules, messages, and learnings.
- Help sites to plan for Phase III (dissemination and sustainability) activities.

As was noted above, during the Phase II period, some sites were still engaged in Phase I development and planning activities. March of Dimes National Office staff spent considerable time working with two sites on finalizing intervention materials and protocols so that they could move on to implementation and evaluation. Additionally, in service of Phase III, March of Dimes staff worked with two sites to develop a replication toolkit and developed the replication toolkit for one site. March of Dimes staff also collaborated with the national evaluators on a manuscript focused on Phase I activities and led the development of two posters for presentation at annual meetings of professional organizations (Society for Public Health Education in 2009 and American Public Health Association in 2010). Upon completion of this report, March of Dimes will collaborate with the national evaluators on a manuscript about Phase II activities.

March of Dimes Chapter staff were also involved in some Phase II activities. In particular, one Chapter collaborated with a local project coordinator to provide recommendations and links to potential Phase II implementation sites.

IV.E. HRSA Project Officer

Throughout Phase II, the HRSA Project Officer Dr. Penny Kyler attended the annual in-person team meetings and quarterly conference calls, reviewed and provided feedback on major deliverables, and provided more informal feedback via phone and Internet. She also circulated training, funding, conference, and publication opportunities that supported the Phase II (and Phase III) goals and activities of the CGEN partners.

IV.F Community Advisory Boards (CABs)

The local sites' CABs were expected to meet periodically during Phase II so that local site staff could provide them with updates on progress and obtain input to implementation and evaluation-related activities. For some sites, CAB activity was not as robust as had been anticipated, and one site's CAB did not meet at all during the reporting period (2007-2010). However, another CAB—Utah's Tongan/Pacific Islander CAB—played a particularly important role in the development and review of the Tongan translations of the evaluation instruments.

IV.G. The CGEN Community

As was referred to above, the CGEN team communicated regularly. Local and national evaluators and March of Dimes project staff met by phone every 3-6 weeks from the first quarter of 2008 through the first quarter of 2010 to discuss progress, deliverables, and challenges. Additionally, the March of Dimes met monthly by phone with the local project coordinators. The entire CGEN team met by phone quarterly and in person annually during Phase II (November, 2007 in Washington, DC; May 2008 in White Plains, NY; February 2009 in Baltimore, MD; and March 2010 in Salt Lake City, UT). The evaluation group met in person in Chicago in December 2007 and then annually thereafter immediately following the all-team in-person meetings. The periodic meetings facilitated mutual support and cross-learning among the group overall and among the evaluators, in particular, as they permitted open discussion of issues in areas such as participant recruitment, instrument design, IRB requirements, data collection strategies, response rate issues, analysis methods, data interpretation, and data presentation formats.

V. Overview of Local Evaluation Elements and Methodologies

V.A. Common Elements

All local evaluations had some common requirements and expectations, including IRB approval, development of logic models, implementation of both process and outcome evaluation activities, and a CBPR approach. While there was also initially an intent to collect data on some common indicators across all local projects, using a common core set of survey items, these plans were abandoned due to the local sites' divergent populations, interventions, and timelines.

Local and national CGEN team members experienced a number of challenges related to cross-site requirements and expectations. Several of these are mentioned briefly in this section; further discussion is provided in Section IX.

V.A.1. IRB Approval

Local evaluations were required to have ongoing IRB approval for their designs, methods, and instruments. Howard and Utah each used their own (university-based) IRB. DWDC and CBWCHC, which did not have their own IRBs, used the UIC IRB, which also served as the IRB of record for the national evaluation effort. During late 2007 and early 2008, a period of turnover among the national evaluation staff (see Section IV.C, above), some confusion and miscommunication arose among DWDC, CBWCHC, and the national evaluation team as to IRB requirements. While this issue was resolved in 2008, in part through discussion of IRB issues at the CGEN in-person meeting in May of that year, it did lead to considerable Phase II implementation and evaluation delays, particularly for CBWCHC (see also Section IX).

V.A.2. Phase II Logic Models

As was indicated in Section I, a *logic model* is a table or diagram that shows the links among a program or project's inputs (resources), activities, outputs, and outcomes. It is a visual representation of a program or project's theory of change (Frechtling, 2007; W.K. Kellogg Foundation, 2004). Logic models are useful tools for designing interventions and evaluations and for communicating with key stakeholders about program objectives and measurement. At the in-person CGEN evaluators meeting in December 2007, logic modeling was reviewed, and an overall logic model for CGEN Phases I-II was drafted. Local evaluators were asked to work with their respective site coordinators to develop logic models for the local interventions. They were particularly encouraged to develop models that reflected common behavioral and social theories underlying effective health promotion interventions (NCI, 2005). According to these theories, factors such as attitudes, self-efficacy, and intentions influence behaviors, which in turn impact health outcomes. It was hoped that logic modeling would help to inform evaluation indicators and instruments, so that measurement would be appropriately aligned with intervention objectives.

While the logic modeling did appear to help advance evaluation planning, it became clear that logic model training and model development would have been most fruitfully implemented early in the intervention planning process (Phase I), when local site stakeholders were initially

developing intervention objectives and activities. In particular, developing logic models early on would have helped ensure that the interventions being planned leveraged documented health promotion best practices as robustly as possible, and that intervention activities and materials were maximally aligned with intervention objectives (see also Section IX).

V.A.3. Process and Outcome Data

All local sites were expected to collect both process and outcome data for their major interventions, including number of participants, the number and nature of activities implemented and materials distributed, participant satisfaction information, and pre- and immediate post-program data on determinants of behavior (e.g., knowledge, intentions, etc.). For additional materials that were leveraged in the major interventions but that could also be used separately (brochures, website, toll-free number), basic process evaluation was considered to be sufficient assessment. Local evaluators developed evaluation designs and instruments in accordance with these expectations.

Early in the project, there were plans to establish some common cross-site indicators and an associated set of common core survey items. However, these plans were abandoned in late 2007, due to the local sites' divergent populations, interventions, and timelines, as well as turnover among national evaluation staff. Sites did ultimately include some similar items in their evaluations. Summaries of these items were recently compiled by March of Dimes staff, and two items (i.e., participants' gender and knowledge of where people get their genes from) are discussed in Section VI.E, below. In hindsight, it would have been helpful for the team to have worked harder to include at least a few common cross-site measures, to permit a "roll-up" or summary of CGEN program reach and effectiveness along key dimensions (see also Section IX).

V.A.4. CBPR Approach

As was indicated in Section I, because the CGEN project espoused CBPR principles and methods, it was expected that community involvement would be robust throughout all project phases. In particular, Phase II implementation and evaluation activities could involve community constituents in a number of ways, including (but not necessarily be limited to) the following:

- Participation of CABs or other community constituents in evaluation design development, instrument development and translation, interpretation of findings, and/or dissemination of findings.
- Involvement of other local community organizations as program implementation sites and participant recruitment partners.
- Participation of community members in intervention delivery and documentation (e.g., as teachers or facilitators).

As is discussed further in Section IX, the local CGEN sites ultimately exhibited different patterns and levels of community involvement in Phase II. In some instances, greater community involvement might have benefited Phase II activities—although as was addressed in the CGEN National Evaluation Phase I report and in the literature (e.g., Cashman et al., 2008), extensive community involvement can also increase project timelines considerably.

V.B. Overview of Timelines, Designs, and Methodologies

As was indicated above, sites were charged with collecting both process and outcome data for the pilot tests of their major interventions. They collected only basic process data on the additional resources (brochures, toll-free number, website) that supported these interventions and served as stand-alone resources. The actual local project implementation and evaluation timelines are summarized in Table 2; the site evaluation designs and methodologies for the major interventions and additional resources are summarized in Tables 3-4, respectively, and are discussed briefly in the subsections below.

Table 2. Site Implementation and Evaluation Timelines (*actual*)

Site	Intervention Approach	Implementation and Evaluation Periods
CBWCHC	Clinic-based pre-counseling workshops	Pilot 1: December 2006-May 2008 Pilot 2: January-February 2009 Pilot 3: June-November 2009
	Brochures	Focus group assessment: January-February 2009 Distribution: December 2006-May 2010
DWDC	Training of CHWs	Training wave 1 (English): May 2008 Training wave 2 (Spanish): February 2009 Training wave 3 (Spanish): November 2009-January 2010, plus follow-up session in March 2010
	Community workshops	Pilot 1: December 2009-March 2010 Pilot 2: April-May 2010
Howard	Community workshops	Pilot 1: March 2008-January 2009 (plus 2-month follow-up data collection) Pilot 2: February-May 2010 (plus 2-month follow-up data collection)
	Website	October 2007 (launch) to May 2010
	Toll-free number	September 2007 (launch) to May 2010
Utah	5th grade curriculum & materials	February-April 2007
	Secondary school materials	March-May 2008
	Community workshops	July 2009-January 2010

Table 3. Evaluation Designs and Methods: Major Interventions

Site	Intervention Approach	Target N	Process Evaluation					Outcome Evaluation				
			Participant Attendance	Participant Demographics	Participant Satisfaction	Topics/activities Checklist	Staff Satisfaction or Other Implem. Assessment	Pre/Post Partic. Survey	Mid-Term Partic. Follow-up	Comparison Group	Assessment of Partic. Outcomes	Staff Assessment
CBWCHC	Clinic-based pre-counseling workshops	40 patients-treatment group 40 patients-control group ¹	X	X	X			X		X	X (genetic counselor survey ²)	X ³
DWDC	Training of CHWs	12 CHWs	X	X	X			X	*			
	Community workshops	250 adults	X	X	X	X	X (CHW/ observer survey)	X	*			
Howard	Community workshops	Pilot 1: 100 adults (50-75 for eval.) Pilot 2: 100 adults for eval.	X	X	X	X	X (facilitator survey)	X	X			
Utah	5th grade curriculum & materials	4 teachers 100 students		X	X		X (teacher survey; students asked if hmwrk done) ⁴	X			X (teacher survey ⁵)	
	Secondary school materials	6 teachers 420 students		X	X		X (teacher survey; students asked if hmwrk done) ⁴	X		X ⁶	X (teacher survey ⁵)	
	Community workshops	100 adults	X	X	X			X				

Notes:

* Originally planned but later dropped.

¹ These were the target numbers for the third pilot (June-November 2009).

² Genetic counselor was asked to provide her impressions of patient learning.

³ Length of appointment with genetic counselor (examined for a subset of evaluation participants only).

⁴ Homework assignments involved sharing class materials with family members.

⁵ Classroom teachers were asked to provide their impressions of student learning.

⁶ For video component only.

Table 4. Evaluation Methods for Additional Materials/Resources

Site	Material/Resource	Focus Group	Usage or Distribution Log	User Survey
CBWCHC	Brochures	X	X	
Howard	Website		X ¹	X
	Toll-free number		X	

Note:

¹ Data were collected on persons who signed up for the mailing list, persons who submitted questions through the website, and persons who submitted the anonymous website survey; the total number of website visitors was not tracked.

V.B.1. CBWCHC

CBWCHC’s pre-counseling workshops underwent pilot testing that included both process and outcome evaluation. Their brochures, which were developed for use both within and separately from the workshops, underwent process evaluation only.

a. Pre-counseling workshops

CBWCHC’s one-on-one pre-counseling educational workshops were evaluated using a pre/post design that included a treatment group and a comparison/control group.⁶ The evaluation design and instruments went through several major revisions. In brief, in an initial pilot assessment conducted from December 2006-May 2008, pregnant patients referred by CBWCHC’s Women’s Health Department for genetic counseling for the first time due to risk factors for thalassemia, abnormal triple screen results, and/or advanced maternal age were asked to participate in the evaluation. Patients who attended CBWCHC’s Chinatown site were assigned to the intervention group and received the pre-counseling genetics education workshop and brochures prior to meeting with the genetic counselor. Patients who attended CBWCHC’s Flushing site were assigned to the comparison group and did not receive the workshop, but instead the standard of care (brochures and appointment with the genetic counselor). Each eligible patient completed a pre-survey and post-counseling survey, as well as a patient satisfaction survey. In addition, the interpreter and genetic counselor provided feedback on their interactions with the patients. However, because IRB approval had not been obtained for the research activities (see Section V.A.1, above), the data were used for internal quality improvement purposes only.

In 2008, the project evaluation was brought in-house to CBWCHC’s Research & Evaluation Unit (see Section IV.B, above), and IRB approval for the research was obtained from UIC. The revised evaluation design and instruments included three multiple choice surveys for intervention participants (baseline, immediately after pre-counseling workshop, and immediately after genetic counseling session) and two for comparison participants (baseline, immediately after genetic counseling session). These surveys addressed knowledge of why one would see a genetic

⁶ In this report, *comparison group* is used as an overarching term, while *control group* is used to refer to a comparison group formed through random or quasi-random assignment. Therefore, in this report CBWCHC’s first two pre-counseling workshop pilots are said to have included a comparison group, while their third pilot is said to have included a control group.

counselor, attitudes toward seeing a genetic counselor in the future, self-efficacy in handling problems in pregnancy, motivation to get genetic testing, and who influences the patient counseling/testing decisions. In addition, the baseline surveys included demographic questions, and the post-surveys included satisfaction questions pertaining to the pre-counseling workshop (treatment group only) and the genetic counseling session. The genetic counselor also completed a survey to assess interactions with the patient, including the counselor's opinion of the patient's prior knowledge, anxiety level, and interaction with the counselor. Oral consent was obtained from pilot study participants; the UIC IRB waived the requirement of written consent to minimize the risk of inadvertently disclosing participant identity. This evaluation methodology was implemented in the second pilot beginning January 2009.

In monitoring outcomes from the second pilot, CBWCHC found that a month into the research, no differences between the study groups were emerging. Possible explanations included (undocumented) differences between the patients seen at the Chinatown and Flushing sites; the use of different interpreters and health educators at the two sites (note that the same genetic counselor worked at both sites, so this was not a potential source of difference); and "survey fatigue" (i.e., a number of patients complained about having to complete so many surveys). In response, CBWCHC stopped the study and made some additional changes to the methodology. Specifically, for a third pilot study, they assigned every other eligible patient to treatment and control groups, respectively, regardless of whether they were being seen at the Chinatown or Flushing site. In addition, the same health educator and interpreter were used at both sites, with all study participants, and were given additional training in survey administration methods. To help address patient "survey fatigue", the second treatment group survey (i.e., the survey implemented just after the pre-counseling workshop) was eliminated, a \$10 giftcard to a popular local bakery was provided to participants as an incentive, and the surveys were color-coded to facilitate staff explanation of survey procedures. The third pilot study was implemented from June-November 2009 and targeted 80 participants: 40 in the treatment group and 40 in the control group. After the main study was completed, CBWCHC retrospectively added an evaluation component, assessment of the length of the genetic counseling appointment among a subset of study patients, using CBWCHC's electronic medical records.

b. Brochures

In January-February 2009, two of CBWCHC's CGEN project brochures (Genetic Testing and Counseling; Amniocentesis) were assessed through one Chinese-language and one Korean-language focus group. Participants were recruited through advertisements in Chinese and Korean newspapers, and by announcement on the Chinese radio station AM 1480 and Korean radio station AM 1650. Persons with the following characteristics were eligible to participate: Mandarin Chinese-speaking or Korean-speaking women who were pregnant or of child-bearing age, limited English proficiency, ages 18-45, residing in New York City. Focus group facilitators followed a focus group guide to obtain oral consent and ask participants a series of questions on the linguistic and cultural appropriateness of the brochures, and their design and readability. A note-taker audio-recorded and summarized the discussions. Focus group participants received \$30 in cash as compensation for their time.

From December 2006 to May 2010, the brochures developed under the CGEN project were distributed to patients and their family members at the CBWCHC Women's Health Department, and at community health fairs and other events, and the volume and venues of distribution were recorded in program logs, when possible. During the period January-March 2007, staff observation of patient reactions to the brochures was also recorded through informal interviews conducted by the local evaluator.

V.B.2. DWDC

At the outset of Phase II, DWDC's CHW training and community workshops were to have similar evaluation designs in which a pre-test survey would collect demographic information and assess baseline knowledge, self-efficacy, and behavioral intentions related to genetics and health; an immediate post-test survey would assess short-term changes in knowledge and intentions, along with participant training/workshop satisfaction; and a follow-up phone interview 2.5 months later would assess whether selected short-term outcomes were sustained and also assess changes in key behaviors. The CHW post-program survey would also include questions about self-efficacy to teach others about genetics and health, and the CHW follow-up interview would gather additional data on the community workshop delivery experience. However, due to project timeline delays, the plans for follow-up interviews with CHWs and community workshop participants were abandoned. In addition, the CHW surveys evolved across three waves of CHW trainings, and changes were made to the planned community workshop evaluation design and instruments to accord with the changes to the community workshop curriculum.

a. CHW trainings

DWDC sought to train at least 12 CHWs and ultimately implemented three waves of CHW trainings. An initial English-language CHW training in May 2008 focused on the six-module curriculum. It employed pre- and post-test surveys addressing participant demographics, knowledge of genetics, selected behaviors (discussion of genetics and family health history with relatives and with health care providers), self-efficacy to make community presentations, and satisfaction with the CHW training. No stipends were provided to CHWs for their participation. Because it was conducted prior to IRB approval (see Section V.A.1, above), the data were used for internal program purposes only.

A Spanish-language CHW training wave in February 2009 was conducted with IRB approval from UIC. It also focused on the six-module curriculum. The participating CHWs provided oral consent and received a copy of the Program Information form (consent script). They did not receive any stipend for participation. The evaluation employed bilingual pre- and post-test surveys (developed by the local evaluator and reviewed by the national evaluation team) addressing participant demographics, knowledge of genetics, past discussion of family health history with relatives and with health care providers (pre-test only), comfort with these behaviors, intention to discuss family health history with relatives and with health care providers, self-efficacy to make community presentations, and satisfaction with the CHW training.

The final CHW training wave was conducted in November 2009-January 2010, with an additional follow-up session in March 2010. Each participating CHW received a stipend of \$300

for participating, and meals and childcare during the training sessions. The evaluation did not include a pre-test survey, due to confusion regarding who would be participating. Specifically, it was expected the same CHWs from the earlier Spanish-language training wave would attend; however, this was not the case—six of the eight participants in the third training wave had never attended a CGEN CHW training before. Because only a (bilingual) post-program survey was implemented, only post-program data on knowledge, behavioral intentions, self-efficacy to make community presentations, and satisfaction with training were collected.

It should be noted that even when the same indicators (e.g., knowledge, behavioral intentions, etc.) were addressed across multiple training waves, the wording of the specific survey questions usually varied. This was due to the team's efforts to refine the measures and their wording, and to the need for concordance between the measures and the curriculum and materials, which underwent multiple revisions during Phase II. In addition, it should be noted that post-tests for the three training waves were administered according to different schedules. For example, the second training wave's post-test was administered several weeks after the last session; the third training wave's post test was administered several weeks after the last main session, but prior to the final follow-up session (which was not anticipated at the time that the post-test was administered).

b. Community workshops

As the third CHW training wave was being planned and the community workshop content and materials were being finalized, DWDC set the target participation in the community workshops at 250 adults. In finalizing the community workshop evaluation design and materials, the team had to consider that at least some participants in module 1 ("Latino/a Families: How to Improve Your Health and the Health of Your Community") would not stay for module 2 ("How to Have a Healthy Pregnancy"). In an effort to streamline the number of surveys that participants would have to complete, the team decided on the following design:

- The *pre-test survey* would address participant demographics, knowledge of genetics (topics from both modules), past discussion of family health history with relatives and with health care providers, and intention to discuss family health history with relatives and with health care providers. It would be administered just prior to the start of the first module.
- The *post-test survey* would address knowledge of genetics (topics from both modules), intention to discuss family health history with relatives and with health care providers, and satisfaction with the workshop. Participants who were leaving at the end of the first module would complete the post-survey *except for the module 2 knowledge questions* just before departing the venue. Participants who were staying to the end of the second module would complete the post-survey (*all questions*) just before departing the venue.

The surveys were largely multiple choice and were made available in English and in Spanish versions. (The translations were developed by the local evaluator and reviewed by the DWDC Project Coordinator, who asked the CHWs for input on selected items, and by the national evaluation team.) An informed consent script was read aloud at the beginning of the workshop, and written copies of the script were provided to participants to keep; the requirement of written (signed) consent was waived by the UIC IRB. Adult workshop participants were given a \$4 New

York City MetroCard for their participation as they left the workshop, regardless of whether they agreed to participate in the evaluation.

The CHWs were initially given responsibility for all data collection activities and were trained in the appropriate procedures during the third wave of CHW training. In particular, they were instructed in how to:

- Have participants mark an attendance sheet at the beginning of each module (no names or addresses were collected, just zip code of residence, age, and gender, so that the total participation in the workshop would be documented and the evaluation participation rate could be calculated);
- Distribute and review consent information;
- Distribute and collect surveys and put them in appropriate envelopes (i.e., separate envelopes for pre-tests, post-tests turned in after module 1, and post-tests turned in after module 2); and
- Complete a post-program Workshop Encounter Form (i.e., a process evaluation checklist and survey) addressing workshop topics covered, any challenges or issues that arose, and other observations.

CHWs worked in pairs to implement community workshops and collect evaluation data. Each was provided a stipend of \$250 for each community workshop that she⁷ co-delivered.

After observing a workshop and analyzing data from most of the workshops conducted from December 2009 to February 2010 (N=82), the local evaluator concluded that there were several problems with the implementation and evaluation procedures. In particular, it appeared that some core workshop content was not being covered, and new topics were being introduced—yet these changes were not being documented in the Workshop Encounter Form. Moreover, the pre/post surveys were not always color-coded in accordance with agreed-upon procedures, workshop participants seemed to be having difficulty with the wording of several survey questions, and there was much missing data. In addition, despite multiple mechanisms to assure that surveys completed by participants attending only module 1 could be distinguished from surveys completed by participants attending both modules, it was ultimately unclear which participants had participated in which modules. These issues raised significant concerns with the validity of the data.

The CGEN evaluation team (local and national evaluators) and March of Dimes staff discussed these concerns at the March 2010 in-person CGEN meeting and decided to stop the community workshop pilot study so that the local evaluator could simplify the wording of several survey questions and revise selected evaluation procedures. In particular, the post-test was split into two surveys. The first post-test survey focused on module 1 knowledge and satisfaction questions, and intention to discuss family health history with relatives and with health care providers. All workshop participants who agreed to participate in the evaluation were to complete this post-test at the end of module 1. The second post-test survey, to be completed at the end of module 2, would focus on module 2 knowledge outcomes and satisfaction. In addition, a new local evaluation team member was also brought on board to handle evaluation procedures at the

⁷ All of the CHWs who facilitated community workshops were female.

community workshops (i.e., completion of the attendance form, implementation of the consent process, distribution and collection of pre/post surveys, completion of the Workshop Encounter Form), so that the CHWs could focus their attention on workshop implementation.⁸ The CHWs also participated in an additional training session on adherence to the workshop module curricula and core activities in March 2010. With these new procedures in place, DWDC scheduled and conducted a second pilot study from April-May 2010.

V.B.3. Howard

Howard's community workshops were assessed in two pilot studies, each of which included process and outcome evaluation components. Their website and toll-free number underwent process evaluation only.

a. Community workshops and booklets

Howard sought to test its community workshops through a pre/post/two-month follow-up design that would assess not only knowledge and intentions, but also behaviors. The primary target audience was African American adults living in wards 1, 4, 5, 7, and 8 of Washington, DC. The workshops were to be implemented in a variety of community settings (e.g., community-based organizations, churches).

Originally, Howard set out to conduct one pilot study of the community workshops, in which an initial test-run workshop would target 7-10 participants, and then ten workshops would collectively reach 100 participants, of whom at least 50-75 would participate in the evaluation. The local evaluator developed the following instruments to collect participant data:

- Registration form to collect contact information;
- Pre- and immediate post-workshop knowledge surveys with yes/no questions on key family health history and race, genetics, and health concepts;
- Post-workshop evaluation form addressing baseline behaviors, workshop satisfaction, and demographics;
- Pledge form to record the health behavior pledge made by each participant at the end of the workshop;
- Pledge follow-up form to record pledge completion information provided by the participant during a brief two-month follow-up phone interview.

All of the pre- and immediate post-program workshop instruments were administered by Howard's CGEN program coordinator, who was also the workshop facilitator, with the assistance of graduate student volunteers from the Genetic Counseling Training Program at Howard. The program coordinator/facilitator and the graduate students were also responsible for obtaining written informed consent from evaluation study participants at the beginning of each workshop. In addition the program coordinator/facilitator completed a Workshop Documentation Form at the end of each workshop. This form captured information on workshop length, location, and staffing; summary participant demographics; activities implemented; and factors facilitating

⁸ The new local evaluation team member spoke Spanish fluently and had considerable experience working as a research assistant, advocate, and counselor with Latino/a women, children, and families in New York City and the Dominican Republic.

or impeding the effective implementation of the workshop. The local evaluator, with the assistance of graduate student volunteers, conducted the two month post-workshop follow-up phone interviews. The only incentives provided to workshop participants were prize items for a recall activity at the end of the workshop (Howard notepads, magnets, etc.).

Community workshops were conducted from March 2008-January 2009. Although the target number of participants was reached (and exceeded), the pilot experienced some implementation challenges. In particular, the length of the workshop varied greatly, due to constraints imposed by the sites that hosted the workshops. Specifically, in a number of instances, the workshop was an “add-on” to another meeting or activity, severely limiting the time available for the workshop and potentially resulting in distraction or fatigue among participants. At least one workshop experienced problems with the physical space (e.g., lighting, temperature). As a result of these circumstances, workshop content tended to vary, and some participants likely had difficulty accessing or assimilating the content. In addition, only 35% of evaluation participants lived in the targeted wards, and 61% of those who indicated their educational level were college graduates, suggesting that they probably had higher socioeconomic levels than the targeted population.

The Howard team, in consultation with the national evaluation team, March of Dimes, and HRSA decided to conduct an additional pilot in which workshop length and content would be more standardized, workshop activities (as implemented) would be more carefully documented by the program coordinator/facilitator through a detailed implementation checklist, and efforts would be made to partner with more organizations that could reach participants from the targeted wards. In accordance with this plan, the local evaluator revised the associated process evaluation instruments. The Howard team also decided that the Stages of Change Model (Prochaska & DiClemente, 1983) would provide the framework for analyzing the second pilot’s intention and behavior data. Specifically, the analysis would assess where participants were along five stages of change (precontemplation, contemplation, preparation, action, or maintenance) for key health-related behaviors. The local evaluator revised the applicable outcome evaluation instruments in accordance with this approach.

In addition, the Howard team reviewed and edited the program materials (including the interactive booklets), in accordance with pilot 1 feedback. The team also obtained IRB approval to offer several incentives to participants: (a) a Howard University hat to all workshop participants; (b) a \$20 grocery gift card to participants who correctly answered questions in a workshop knowledge recall activity; and (c) a \$10 grocery gift card for participation in the two-month follow-up interview. Another team decision was to distribute the evaluation knowledge questions—with the correct answers—to participants just before they left the workshop, to help ensure that they would leave the venue with correct information. Workshops for the second pilot study were conducted from February-May 2010; the objective was to deliver ten workshops and reach 100 participants. The two-month follow-up interviews with workshop participants were completed as planned.

It should be noted that the interactive booklets used in the workshops, which were also available as stand-alone resources, were evaluated for participant satisfaction in several ways. In particular, in fall 2008, one focus group with African Americans was conducted to assess the

booklets, and a review and survey were also conducted with members of the National Black Nurses Association. Additionally, questions about the booklets were included in the post-workshop evaluation form completed by pilot study 1 and 2 workshop participants. The booklets were revised after pilot study 1 (as noted above) in accordance with this feedback and the pilot 1 outcome evaluation findings.

b. Website

The project coordinator provided information about the website to community members during community workshops and dissemination events. The website information was also highlighted in the two interactive booklets used at community workshops and other community events.

The website was evaluated during the period December 2007-May 2010. The evaluation was limited to basic process data. In particular, the Project Coordinator prepared a monthly report on number of visitors making inquiries, number of visitors requesting to join the mailing list, and number of visitors completing the anonymous Web Site Questionnaire. The questionnaire can be reached via a link on the home page. It comprises a short set of multiple choice questions on website satisfaction, how the user heard about the website, and user demographics. Unfortunately, the Webmaster did not track overall number of website hits, page views, or visitors, so data on overall site usage are unavailable.

c. Toll-free number

The project coordinator informed local community members about the toll-free number at community workshops and other community events. The toll-free number is also displayed on the Howard CGEN website and on the workshop materials.

The toll-free number, like the website, underwent basic process evaluation from December 2007-May 2010. The Project Coordinator used a Toll-Free Number Questionnaire to gather basic demographic information on each caller, as well as data on how the caller got the number, the topic of the call, and any other comments callers wished to make.

V.B.4. Utah

a. Fifth grade Hispanic/Latino curriculum and materials

After submitting a research study proposal to the Salt Lake City (Utah) School District and obtaining approval, GSLC staff worked with the Salt Lake City School District Science Specialists to identify appropriate teachers for the fifth grade pilot study. The GSLC then sent a letter to the relevant school principals explaining the project and asking for their agreement to have their teachers be involved; the Science Specialist facilitated obtaining these permissions. Participating teachers were required to teach all of the activities, complete a lengthy teacher survey, and administer student pre- and post-tests. All received a 1.5-hour training in which they were introduced to the materials and activities and given instructions on completing the evaluation. Each teacher provided informed consent to participate and received a \$200 stipend

upon completing the study requirements. The target participation for this pilot study was four fifth grade teachers and 100 students.

The pilot study was implemented from February-April 2007. The student evaluation used pre/post surveys that included mainly closed-ended questions. The pre-test survey, which was administered just before delivery of the curriculum, assessed knowledge of relevant genetic concepts and students' confidence in their knowledge of these concepts. It also collected basic demographic information from students. The post-test survey, which was administered just after completion of the curriculum, included the same knowledge and confidence-in-knowledge questions as the pre-test, and also asked students to indicate what they had learned from the curriculum, whether they had spoken with anyone in their family about genetics, whether they had shown the take-home worksheets to anyone in their family, whether they had enjoyed learning about genetics, and whether they would like to learn more about genetics.

The student surveys were made available in both English and Spanish; the translation of the original English instruments to Spanish was prepared by the UIC Midwest Latino Health Research, Training & Policy Center. Since the student surveys were anonymous to the evaluator, informed student consent was waived by the Salt Lake City School District and thus by the University of Utah IRB. Students had to be in class when the surveys were administered in order to participate in the evaluation, and thus all students who provided matched pre/post surveys participated in the first and last curricular activities; however, beyond this, student attendance or dosage data were not collected.

The teacher survey elicited the following information: (1) descriptions of teachers' classes, including grade level, number of students, type of class, instructional setting, and classroom demographics (gender, race, and ethnicity); (2) specific evaluations of each of the curricular activities, including perceived cultural appropriateness (note that teachers were not members of the Hispanic/Latino community), how engaged students were, level of difficulty, intention to use the activity again in the future, etc.; and (3) open-ended responses about the overall curriculum, including strengths and weaknesses, suggestions for improvement, whether students seemed to share the information with their families, and whether students seemed to be more interested in and engaged with the materials because they were available in Spanish. Teachers were not supervised during the field test. However, the evaluator visited each classroom once to informally observe each teacher teaching one of the five activities.

b. Secondary school Hispanic/Latino materials

After submitting a research study proposal to the Salt Lake City School District and obtaining approval, GSLC staff worked with the Salt Lake City School District Health Specialist and the Ogden (Utah) School District Health Specialist⁹ to provide the names of secondary schools in their districts that they thought might have health education teachers who would be interested in participating in the pilot study. The GSLC then sent a letter to the relevant school principals explaining the project and asking for their agreement to have their teachers be involved. After receiving principals' approvals, the GSLC contacted the schools' health education teachers to invite them to participate. Each teacher had to be teaching at least two sections of health

⁹ The Ogden School District does not have a formal research study request process.

education to be eligible, so that he or she could assign half of the classes to receive all activities, including the video, and the other half of the classes to receive all activities except for the video. The assignment of classes to the video vs. non-video conditions was made by the teacher, and reflected his or her preference. The target participation for the pilot was six teachers and 420 students.

Teachers had to agree to follow a specific lesson plan, complete a lengthy teacher survey, and administer student pre- and post-tests. All received a one-hour GSLC training in which they were introduced to the materials and activities and given instructions on completing the evaluation. Each teacher provided informed consent to participate and received a \$200 stipend upon completing the study requirements.

The pilot study was conducted from March-May 2008. The student evaluation used pre/post surveys that included mainly closed-ended questions. The pre-test survey, which was administered just before implementation of the intervention activities, assessed knowledge of genetics and confidence in knowledge of genetics. It also collected basic demographic information from students. Two versions of the post-test survey were developed: one for students who watched the video and the other for students who did not. Both versions were administered to the respective students just after completion of the intervention activities. In addition to including the same pre-test knowledge and confidence-in-knowledge questions, the surveys asked students to indicate what they had learned from the module, whether they had completed a family health history with their families (and barriers to doing so), whether they would want to learn more about how to use family health histories to lead a healthier life, and their reactions to the materials. The post-test for the students who had watched the video also included specific satisfaction questions about the video.

The student surveys were made available in both English and Spanish; the translation of the original English instruments to Spanish was prepared by the DWDC local evaluator. Since the student data were anonymous to the evaluator, informed student consent was waived by the Salt Lake City School District and thus by the University of Utah IRB. As in the case of the fifth grade field test, students had to be in class when the surveys were administered in order to participate in the surveys, and thus all students who provided matched pre/post surveys participated in the first and last curricular activities; however, beyond this, student attendance or dosage data were not collected.

The teacher survey elicited information on: (1) descriptions of teachers' classes, including grade level, number of students, type of class, instructional setting, and classroom demographics (gender, race, and ethnicity); (2) specific evaluations of each of the activities, including cultural appropriateness, how engaged students were, level of difficulty, intention to use the activity again in the future, etc.; and (3) open-ended responses about the overall curriculum. Teachers were not supervised or observed during the field test.

c. Tongan community workshops

In April 2009 the GSLC collaborated with the National Tongan American Society (NTAS) to train the Tongan/Pacific Islander CAB members (including the NTAS Director) and two

instructors in delivery of the intervention, and to recruit community workshop implementation sites. Each participant in this three-hour training workshop received a \$25 gift card, and a \$3,000 mini-grant was provided to NTAS to support staff time in arranging for venues and participants, and preparing and presenting the workshops. Potential community workshop sites included churches, senior centers, and other community organizations. The target for community workshop participation was a total of 100 adults. As was indicated above, the workshop materials were translated into Tongan only, but not into other Pacific Island languages, so the primary target population for the pilot study was Tongan.

The workshop evaluation used pre/post surveys. Closed-ended questions assessed knowledge of selected genetics and health concepts, confidence in that knowledge, and beliefs about ability to reduce risk of developing diseases that run in their families. The pre-test also collected demographic information, as well information on why participants were attending the class. The post-test also asked participants to indicate two things they had learned in the class, and assessed whether they were interested in learning more about inherited traits and diseases, whether they planned to talk to family members about family health history, whether they planned to collect a family health history, and whether they planned to make lifestyle changes based on what they had learned (and if so, what changes; if not, why not). Finally, at post-test participants were also asked how much they enjoyed the class, how much the activities helped them to understand the material, and what they liked best and least about the class. The pre/post surveys were made available in a bilingual English/Tongan format. The survey translation was carried out by the NTAS Director and reviewed by other members of the Tongan/Pacific Islander CAB. A waiver of informed consent was obtained from the Utah IRB for participation in the pilot study. No incentives were provided to community workshop participants.

The community workshops were delivered from July 2009-January 2010. All workshops were delivered in Tongan by the NTAS Director, who also administered pre/post surveys to intervention participants.¹⁰ This administration process included not only distributing and collecting the written surveys, but also reading questions aloud to the group (as needed) and helping individual participants with limited literacy skills to understand the questions and indicate their answers. Delivery of the workshops was not supervised by the evaluator. However, a GSLC Research Associate working on the CGEN project (who did not speak Tongan) observed one of the workshops and wrote a report for the local evaluator. The workshop instructor did not complete any written implementation assessment instruments, but did provide oral feedback.

¹⁰ A GSLC staff member also delivered the workshop in English to a group of bilingual Tongan youth, but this group was not part of the evaluation study.

VI. Overview of Local Evaluation Findings

Local evaluators have prepared detailed Phase II reports on their respective sites' CGEN interventions. An overview of intervention reach is provided in Table 5 (below), and an overview of outcome evaluation findings for the major interventions is provided in Table 6, (below). A site-by-site summary and discussion of evaluation findings, limitations, and implications is provided in the subsections below. It draws heavily from the local evaluators' reports but also includes additional perspectives from the national evaluators and broader CGEN team.

VI.A. CBWCHC

VI.A.1. Pre-Counseling Workshops

As was discussed above (see Section V.B.1), CBWCHC conducted process and outcome evaluation of its pre-counseling workshops in a series of pilot studies. The first study was implemented without IRB approval; its findings were used for internal quality improvement only. The second pilot was stopped early because of a recognized need for methodological changes. The third pilot was implemented from June-November 2009 and was the focus of CBWCHC's Phase II evaluation report. Key findings, limitations, and implications are summarized below.

a. Findings

The study included 44 intervention group participants, who received the pre-counseling workshop (including brochures) just prior to meeting with the genetic counselor, and 42 control group participants, who received the genetic counseling appointment and brochures only. These numbers slightly exceeded the targets (40 intervention, 40 control). Overall, intervention and control group patients were very similar along the various demographic dimensions that were measured, except that intervention participants were somewhat more likely to report their English proficiency as "poor/none" than control group participants.

Analysis of the pre/post survey data found that intervention patients exhibited significantly greater improvements than control patients for knowledge of why one would see a genetic counselor, attitudes toward seeing a genetic counselor, and self-efficacy for handling problems in pregnancy. However, the control patients did exhibit higher baseline scores for these indicators than the intervention patients, and so had less room for improvement (see also below).

In addition, the genetic counselor was more likely to report that intervention patients (vs. control patients) showed evidence of knowing why they had been referred for genetic counseling. Moreover, among the subset of patients for whom length of genetic counseling appointment was examined, intervention patients showed a 40% shorter appointment length than control patients. Both groups reported similarly high levels of satisfaction with the genetic counseling session, and the intervention group reported high satisfaction with the pre-counseling workshop.

Table 5. Summary of Intervention Reach

Site	Intervention Approach	Target Intervention Participation	Actual Intervention Reach
Major Interventions			
CBWCHC	Clinic-based pre-counseling workshops	40 patients, treatment group (and 40 patients, control group) ¹	Pilot 1: 137 patients (91 treatment, 46 comparison) Pilot 2: 30 patients (18 treatment, 12 comparison) Pilot 3: 86 patients (44 treatment, 42 control)
DWDC	Training of CHWs	12 CHWs	Training wave 1: 7 CHWs Training wave 2: 9 CHWs Training wave 3: 8 CHWs (including 3 who also participated in wave 2) Total of 21 CHWs trained 7 CHWs implemented community workshops
	Community workshops	250 adults	Pilot 1: 118 (13 workshops) Pilot 2: 153 (12 workshops) ²
Howard	Community workshops	100 adults	Pilot 1: 178 adults ³ Pilot 2: 218 adults
Utah	5th grade curriculum & materials	4 teachers 100 students	6 teachers; 178 students
	Secondary school materials	6 teachers 420 students	6 teachers; 562 students
	Community workshops	100 adults	97 adults
Additional Materials/Resources			
CBWCHC	Brochures	--	17 focus group participants (12 Chinese, 9 Korean) 7,273 brochures distributed (December 2006-May 2010)
Howard	Website	--	Total number of visitors (December 2007-May 2010) is unknown ⁴ ; however: -10 people submitted inquiries through the website -13 people completed the Web Site Questionnaire -164 people joined the Howard CGEN mailing list via the website.
	Toll-free number	--	5 calls; additional calls were wrong numbers (December 2007-May 2010)

Notes:

¹ These were the target numbers for the third pilot (June-November 2009).

² One additional workshop was implemented in pilot 2 (at a senior center), but the participants experienced problems with retention, motivation, and completion of the program evaluation tools. The participants were excluded from the Actual Intervention Reach count provided here and from the pilot 2 study.

³ This is the number of workshop participants that consented to participate in the evaluation. Data on the total number of workshop participants are unavailable.

⁴ The Webmaster did not collect data on total number of visitors to the site.

Table 6. Summary of Evaluation Sample Sizes and Outcome Evaluation Findings

Sites	Intervention Approach	Evaluation N	Knowledge	Attitudes, Self-Efficacy, &/or Beliefs	Satisfaction w/ Subsequent Care	Intentions	Health Behaviors	Other
CBWCHC	Clinic-based workshops	86 ¹ (44 I, 42 C)	++ (I vs. C, pre to post)	++ (I vs. C, pre to post)	NS (I vs. C, post only)	N/A	N/A	+ (length of appt. w/ gen. counselor, I vs. C)
DWDC ²	Community workshops: Pilot 1	114 adults	++ ³	N/A	N/A	++	N/A	N/A
	Community workshops: Pilot 2	133 adults	++	N/A	N/A	++	N/A	N/A
Howard ⁴	Community workshops: Pilot 1	178 adults	++ ⁵ (pre to post)	N/A	N/A	+ (post only)	+ (pledge fulfillment; post only)	N/A
	Community workshops: Pilot 2	183 adults	++ ⁶ (pre to post)	N/A	N/A	+ (post only)	+/- ⁷ (pledge fulfillment; stages of change)	N/A
Utah	Fifth grade curriculum/materials	6 teachers; 159 students for outcomes; 169 students for satisfaction	++ (pre to post)	++ (confidence in knowledge) + (interest to learn more; post only)	N/A	N/A	N/A ⁸	N/A
	Secondary school curriculum/material	6 teachers; 404 students	++ (pre to post)	++ (confidence in knowledge) + (interest to learn more; post only)	N/A	++ (students who saw vs. didn't see video, post only ⁹)	N/A ⁸	N/A
	Community workshops	95 adults	++ (pre to post)	NS (belief ¹⁰) + (interest to learn more; post only)	N/A	+ (post only)	N/A	N/A

Key: ++ = One or more statistically significant positive findings; + = One or more “clinically positive” findings, no test of statistical significance; - = One or more “clinically negative” findings, no test of statistical significance; NS = not statistically significant; I = intervention group; C = comparison group; N/A = Not applicable because not measured.

Notes:

¹ The numbers in this cell reflect the third pilot.

² The CHW trainings had very small Ns, variable attendance, and pre/post matching challenges, and the third training wave had no pre-test. Results are not summarized in this table but are discussed briefly (in largely qualitative terms) in the main report body, below.

³ Significant positive findings were found for selected aspects of genetics and health knowledge; pilot 1 healthy pregnancy knowledge findings were set aside due to methodological issues.

⁴ Note that methods of statistical assessment for the knowledge items differed across Howard’s pilot 1 and pilot 2, so the findings from the two pilots are not directly comparable.

⁵ Statistically significant positive outcomes were found only among certain subpopulations, within particular knowledge categories.

⁶ Change in overall knowledge score for family health history was not significant. Change in overall knowledge score for race, genetics, and health was significant.

⁷ Only limited analyses of the follow-up behavioral data had been carried out as of the time this report was being finalized. Some positive and some negative changes in both activities pledged to and activities not pledged to were identified.

⁸ Evaluation of Utah’s school-based interventions included assessment of whether students shared materials with their parents, but as this sharing was done as part of homework assignments (which were intervention components), measurement of these student behaviors has been treated in this report as part of process evaluation, not outcome evaluation.

⁹ Analysis of post-test intention (i.e., to complete family health history) was limited to students who did not complete the family health history homework assignment.

¹⁰ Belief that diet and exercise could reduce chances of getting inherited disease was essentially at ceiling at baseline and did not change significantly at follow-up.

b. Limitations

The pre-counseling workshop study had several key limitations. In particular, as was noted above, despite the quasi-random assignment procedures, the control group was closer to ceiling at baseline and so had less room for improvement than the treatment group. The reasons for the baseline differences between the groups are unclear, but may relate to the small study sample size (which may have resulted in undocumented differences between the two groups); assignment procedures; and/or a differential Hawthorne Effect¹¹ between the groups, given the different conditions under which the baseline surveys were administered (i.e., the health educator administered the baseline survey to the intervention group, the interpreter administered it to the control group). In addition, the workshop was offered only in Mandarin and attracted a large number of participants from one particular province in China, so the findings may not be generalizable to women from other parts of China. The assessment of genetic counseling appointment length was also limited to a subset of study participants, due to data availability considerations, and there was no mid-term or long-term follow-up to assess changes or differences in study participants' behaviors.

c. Discussion and implications of findings

In spite of the limitations noted above, the study's findings for patient knowledge, attitudes, self-efficacy, and appointment time with genetic counselor were promising. A replication study with a larger sample size, survey administration by the same staff across all timepoints and groups, and greater attention to assessment of treatment and control condition costs (i.e., cost of genetic counselor's time, interpreter's time, and health educator's time) could shed further light on the cost-effectiveness of the pre-counseling workshop.

The study's efforts to monitor outcome data and make associated adjustments to procedures (i.e., from pilot 2 to pilot 3) were very fruitful. The site experienced tensions between the needs of service vs. research activities, but achieved an appropriate balance—which is particularly noteworthy in a “real world” evaluation context—through open, ongoing communication and collaboration among program and research staff.

VI.A.2. Brochures

Two focus groups (one with 12 Chinese women, one with 9 Korean women) were conducted in January-February 2009 in the respective languages (Mandarin, Korean) to assess the cultural and linguistic appropriateness, content, and ease of understanding of the Genetic Testing and Counseling brochure and the Amniocentesis brochure. The principle recommendations from the groups were that the brochures have more color and images, that clinical terms be defined in layman's language, and that contact information be made more prominent. CBWCHC plans to update the brochures, based on this feedback.

¹¹ The Hawthorne Effect is the tendency of research participants to act differently from how they would normally act (e.g., respond differently to a survey) because they know they are being studied (http://www.ojp.usdoj.gov/BJA/evaluation/glossary/glossary_h.htm).

Overall, focus group participants also indicated that they learned more about genetic testing and amniocentesis from the brochures. Chinese participants unanimously agreed that the brochures changed their opinion about getting an amniocentesis test, in light of the importance of genetic testing. Generally, Chinese focus group participants demonstrated greater motivation to learn more about genetic testing. Korean participants were generally well-informed about genetic testing prior to attending the focus group and did not have negative feelings towards testing and amniocentesis. Focus group participants expressed willingness to share the brochures with family members and friends, and particularly with pregnant women, to inform them about the availability of genetic testing.

Per CBWCHC logs, the total number of brochures distributed from December 2006-May 2010, was 7,268. The Family Health History brochure was developed later than the other brochures (summer of 2008), with supplemental CGEN funds. It is interesting to note that there was a large increase in distribution of this brochure from the 2008-2009 project year, in which only 126 were distributed (i.e., the fewest of any of CBWCHC's CGEN brochures), to the 2009-2010 project year, in which 567 were distributed, making it the second most commonly distributed brochure that year (after Maternal Serum-Triple Screen, of which 836 were distributed). Family health history is central topic in the other CGEN sites' interventions, and has proven to be a topic of great interest across the diverse populations reached with the CGEN interventions and materials (see below).

VI.B. DWDC

As was discussed above (see Section V.B.2), DWDC collected process and outcome evaluation data on three waves of CHW trainings and two community workshop pilot studies. The findings from the CHW trainings are discussed below in qualitative terms, given the very small sample sizes, variable attendance, pre/post data matching challenges, and the lack of pre-test for participants in the third training wave. The more robust quantitative findings, limitations, and implications from the two community workshop pilot studies are also summarized below.

VI.B.1. CHW Trainings

a. Findings

The first training wave (May 2008) was conducted in English and focused on the original six-module curriculum. It was delivered by DWDC's first CGEN Project Coordinator, who had left her position by the time of the training but returned to serve as a contracted trainer. Four sessions totaling 13 contact hours were delivered to seven participants, four of whom had been involved with development of the six-module workshop curriculum. Analysis of the limited pre/post survey data available from training wave 1 suggested that among the CHWs, knowledge of genetics may have improved for some items but not for others. In addition, self-efficacy to present to, reach out to, and educate others in the community appeared to have declined from pre-test to post-test per several survey measures (although self-efficacy did appear to have increased per at least one measure). The declines were likely due to the complexity of the curriculum, even though feedback on satisfaction with the training was positive overall.

The second training wave (February 2009) was conducted in Spanish by DWDC's second CGEN project coordinator. It also focused on the six-module curriculum. Three sessions totaling 11 contact hours were delivered; nine CHWs attended. However, the training was discontinued after the third session (i.e., before completion of the training series) because of CHWs' concerns about the content and curriculum. Specifically, they reported that there was just too much material to absorb and to teach to others. Analysis of the available pre/post data (all data, not just matched surveys) suggested that knowledge of genetics had increased from pre- to post-test, but that intentions to discuss family health history with family or providers within the next three months were unchanged. Self-efficacy to present to, reach out to, and educate others did not appear to have changed much, overall.

The third training wave was conducted in Spanish by DWDC's second CGEN project coordinator. Six sessions (totaling over 13 hours of training) were delivered from November 2009-January 2010. The sessions focused on the newly revised and streamlined two-module curriculum. Specifically, they employed the final CHW training guide and the community workshop participant workbook and flipcharts, and they afforded CHWs several opportunities to practice their presentation and facilitation skills through mock presentations. A local genetic counselor who had worked extensively in the community attended much of the training and provided supplemental information to the group. In addition, the local evaluator provided evaluation procedure training, so that the CHWs would have the appropriate knowledge and skills to provide consent information to community workshop participants, administer the community workshop surveys, and document workshop implementation.

A total of eight CHWs participated in training wave 3. As was discussed above (see Section V.B.2.a), only a post-test was implemented. At post-test, genetics knowledge scores were high, intentions to talk with family and a health care provider about family health history were relatively high, and self-efficacy to present to, reach out to, and educate others in the community was high. Feedback on the training was also very positive.

An additional follow-up two-hour capacity-building session (conducted after the post-test) was implemented between the first and second community workshop pilot studies (March 2010). It focused on intervention protocol fidelity. A total of five CHWs participated.

Overall, a total of 21 individuals participated in CHW training sessions, most of whom were women. Attendance was variable within each training wave, and there was very little participant overlap across training waves—a total of three CHWs participated in both wave 2 and wave 3. Ultimately, only seven of the 21 CHWs who had participated in CHW training delivered any community workshops; all of them were women who participated in training wave 3. The principal reasons why many CHWs participated in training sessions but did not go on to deliver community workshops included:

- the long delay (for training wave 1 and wave 2 participants) between training and implementation of the community workshop, during which time some CHWs' availability changed (e.g., due to new jobs) and/or interest in CGEN waned;
- personal health issue (n=1) or death of the CHW (n=1);
- departure from the New York area (n=1, unconfirmed).

Across the training waves, the CHWs made important contributions to the development and revision of the community workshop curriculum and the CHW training materials. They also provided some input to the community workshop surveys. All of these contributions helped to ensure that the materials would be maximally appropriate for and accessible to local community members. Overall, the local evaluator noted that there was considerable discussion in all of the training waves about family health history, and the CHWs appeared to show increased recognition of the importance of family health history to one's health. Additionally, the CHWs who did deliver workshops generally reported that it was a very positive experience. As of the writing of this report, a number of them are now working as CHWs or other health information brokers in community-based settings. In particular, one CHW is working for the Latino Commission on AIDS, several are working on a research project with Columbia University's Herbert Irving Comprehensive Cancer Center as interviewers, and others are working within DWDC with the HIV Prevention Program.

b. Limitations

There were numerous methodological challenges with the CHW training surveys, such as small sample sizes, variable CHW attendance, changes in instruments over time, missing data, delayed collection of post-test data, and lack of a pre-test for training wave 3. These challenges made it difficult to offer valid interpretations of the survey findings.

A more systematic assessment of CHW outcomes and inclusion of a longer follow-up period—including after CHWs had delivered trainings—would shed further light on outcomes of the CHW training. A follow-up interview (which was originally planned by the local evaluator, but abandoned due to time and resource constraints) would likely offer a particularly rich source of data on the impact of training and workshop delivery on the CHWs.

c. Discussion and implications

Although it can be very time-consuming to involve CHWs in development and refinement of program curricula and materials, their input can help to ensure that these resources are culturally and linguistically appropriate for local community constituents. However, CHWs also tend to have numerous responsibilities that compete for their limited time; in some cases, these may be the same health-related considerations (i.e., their own health problems, care of loved ones) that had prompted them to become involved in CHW activities to begin with. Laying out realistic timelines and specific tasks for CHW involvement, and adhering to them, can help ensure that CHWs make informed commitments to project work and can honor those commitments. Ultimately, CHWs can benefit in a myriad of ways from facilitation training and workshop delivery experiences, including gaining skills and self-efficacy that can serve them in other paid and volunteer activities. Ultimately, these activities can also have many benefits for the broader community. A combination of quantitative and qualitative methods can help to capture these outcomes validly and authentically.

VI.B.2. Community Workshops

a. Findings

As was discussed above (see Section V.B.2.b), several months into its community workshop pilot, DWDC's local evaluator noted methodological challenges that led the team to stop the pilot, make some revisions to evaluation methods and instruments, and implement a second pilot. For both pilots, workshops were organized in collaboration with other community groups and implemented in a variety of community settings—such as DWDC's offices, community-based organizations, schools (during after-school hours), and private residences. Together, the two workshop pilot studies reached a total of 271 adults, exceeding the target of 250. Of these attendees, 247 participated in the evaluation. Process and outcome evaluation were conducted in both pilot studies.

The first pilot, conducted from December 2009-February 2010, included 13 workshops that reached 118 adult participants; 114 attendees participated in the evaluation. Of those who participated in the evaluation and responded to a question about gender, 83% were female. Analyses of the pre/post data showed that genetics and health (module 1) knowledge increased significantly overall from pre- to post-test. Older participants, those with lower formal education, and men showed greater knowledge increases than other groups. Healthy pregnancy (module 2) knowledge data were set aside, due to methodological concerns; specifically, it was not possible to identify which workshop participants had stayed for that module. Intentions to talk with family and with health care providers about family health history increased significantly from pre- to post-test. Post-program feedback on materials, facilitation, and learning were very positive, and over 94% of participants indicated that they would recommend the workshop to a friend. The main criticism of the workshop was that it was too short (65% of participants).

As was indicated in Section V.B.2.b, methodological challenges with the first pilot included: core workshop content not being covered and new topics being introduced (without associated documentation in the Workshop Encounter Form); lack of survey color-coding in accordance with agreed-upon procedures; workshop participant difficulty with the wording of several survey questions; and much missing data. These issues raised significant concerns with the validity of the data. Many of these challenges seemed to be addressed successfully in the second pilot, however, through changes to instruments and procedures (see Section V.B.2.b for details).

The second pilot, conducted from April-May 2010, delivered a total of 13 workshops, but only 12 were included in the evaluation. At the additional workshop, which was conducted at a senior center, the participants experienced problems with retention, motivation, and completion of the program evaluation tools. Data from this workshop were therefore excluded from the pilot 2 evaluation. The remaining 12 workshops reached a total of 153 adult participants; 133 attendees participated in the evaluation, of whom 86% were female. Analyses of the pre/post data showed that genetics and health (module 1) knowledge increased significantly overall from pre- to post-test, as did healthy pregnancy (module 2) knowledge. Intentions to talk with family and with health care providers about family health history also increased significantly from pre-test to post-test. Moreover, post-program feedback on workshop length, materials, facilitation, and

learning were very positive, and close to 99% of participants indicated that they would recommend the workshop to a friend. Overall, pilot 2 had very low rates of missing data.

b. Limitations

The methodological challenges of pilot 1 and the resultant concerns with data validity were summarized above. Pilot 2 addressed a number of those concerns successfully, although some issues concerning the pre/post survey questions remained. In particular, for several of the pilot 2 module 1 and module 2 knowledge questions, knowledge was already at ceiling or close to ceiling at pre-test, which limited the potential for knowledge score improvement. Moreover, even though the question on the influence of the environment on health was re-worded from pilot 1 to pilot 2, participants in pilot 2 still seemed to have some challenges with this question. It is unclear whether this was due to unresolved issues with the question wording, lack of clarity in the curriculum concerning the definition of environmental influences on health, or both.

A limitation for both pilot studies was inclusion of only short-term (i.e., pre- and immediate post-test) follow-up. As such, it was not possible to measure maintenance of short-term changes over time, or longer-term behavioral changes, for which inclusion of a comparison group would have strengthened evidence for a causal link between the intervention and changes reported by participants.

c. Discussion and implications of findings

Despite some ongoing instrument concerns, findings with respect to knowledge, intentions, and satisfaction from the second community workshop pilot study were very promising. It is particularly noteworthy that the second pilot had, overall, a very low rate of missing data, despite the fact that many participants had limited literacy skills. Efforts to adjust the instruments and administration processes following the first pilot—including the addition of a third party to handle evaluation activities, so that CHWs could focus on workshop facilitation—likely played an important role in keeping the missing data to a minimum.

Future research on the DWDC community workshop might include longer-term follow-up of participants—perhaps by phone interview (as was originally proposed by the local evaluator) to look at maintenance of short-term changes in behavioral determinants and mid-term behavior changes. In addition, the extent to which the community workshop materials are linguistically and culturally appropriate “as is” for other Latino/a communities (for example, Mexicans and Mexican Americans in more rural areas) is an important question. Efforts to adapt (as appropriate), replicate, and re-evaluate the workshops with such communities would be a fruitful path for a future project, particularly given the size and growth rate of the U.S. Latino population.

VI.C. Howard

As was discussed above (see Section V.B.3), after conducting an initial dry-run with 15 participants, Howard conducted two pilot studies of their community workshops, each of which included process and outcome evaluation components. Key findings, limitations, and

implications are discussed below. In addition, Howard collected process data on usage of the website and the toll-free number; these findings are also summarized below.

VI.C.1. Community Workshops and Booklets

a. Findings

The first pilot comprised nine workshops held in community centers, churches, and (in one case) a hotel meeting room. A total of 178 adult attendees consented to participate in the evaluation, most of whom were women (i.e., 74% of those who identified their gender); information on the total number of workshop attendees was not collected. The number of evaluation participants considerably exceeded the target of 100 workshop participants and 50-75 evaluation participants. Seven of the workshops were held in the targeted Washington, DC wards.

Analysis of the pre/post knowledge questionnaires showed that the percent of respondents answering correctly increased for some knowledge items and decreased for others, for both the family health history (FHH) survey and the race, genetics, and health (RGH) survey. Participants under age 55 showed a statistically significant increase in the overall FHH knowledge score, while participants with a college degree showed a statistically significant increase in the overall RGH knowledge score. Participants who were both under age 55 and holders of a college degree also showed a statistically significant increase in the overall RGH knowledge score. No other statistically significant knowledge changes emerged. It should be noted, however, that rates of missing values for the individual knowledge items were fairly high (15-20%), and missing rates were even higher when items were aggregated into mean knowledge scores and demographic characteristics were taken into account.

Of the 178 evaluation participants, 90% pledged in writing to engage in one of ten health-related behaviors during the two months after the workshop. The most common pledge was to discuss FHH with members of family. Two-month follow-up interviews revealed that of the 160 participants who had made a pledge, 55% reported achieving their pledge, 23% reported not achieving their pledge, and 23% did not provide follow-up data (i.e., the phone number they had provided was disconnected or they did not respond to the follow-up call). Additional analyses showed that participants indicating that they had already done particular activities, as of pre-test, were more likely to select those same activities for their pledge and were more likely to engage in those activities post pledge, as opposed to participants who had indicated that they had not already done the activities as of pre-test. A sizable minority of those who had made a pledge reported engaging in more than one of the pledge list behaviors during the follow-up period.

The vast majority of participants rated the workshop content, delivery, and materials (including the booklets) very highly. Suggestions for changes to the booklets offered by workshop participants, a separate focus group, and National Black Nurses Association members who reviewed the booklets and commented on them via a separate survey were all used to revise the booklets after the first pilot. In particular, changes were made to better reflect both genders, and to make the overall cover designs of the two booklets complementary. In addition, to better accommodate low-literacy and low-vision individuals, the font size was increased to at least 12-point, all-capital-letters and italics were replaced with boldface; and red, orange, and yellow font

and highlights were eliminated. Also, all text was left-aligned to provide more white space. The family health history insert was amended to provide space for the user's offspring.

The knowledge findings—improvements in only some areas, among only certain groups—were difficult to interpret. In reviewing the data, the team concluded that the mixed findings might be the result of several workshop implementation challenges. In particular, as was discussed in Section V.B.3.a, the length of the workshops varied greatly, and several factors related to workshop setting may have made it challenging for some participants to access or assimilate the content. A relatively high rate of missing knowledge data was also a concern, as noted above. In addition, questions were also raised about the fact that only 35% of evaluation participants lived in the targeted wards, and 61% of those who indicated their educational level were college graduates, suggesting that they probably had higher socioeconomic levels than the targeted population. Finally, there was no framework or point of comparison for assessing whether workshop participants' pledge completion rates constituted "success".

The second pilot was successful in addressing a number of these concerns. In particular, workshop content and length were more standardized, and through additional outreach to community organizations, arrangements were made to conduct all workshops in the targeted wards. Specifically, a total of eight community workshops were held in community centers, churches, a public charter school, and at Howard. These workshops reached 218 participants; 183 consented to participate in the evaluation, considerably exceeding the target of 100 workshop participants. The majority of evaluation participants (72%) reported residing in the targeted wards, and of the evaluation participants who reported their educational level, only 27% were college graduates—far fewer than the 61% in the first pilot, suggesting that pilot 2 participants were, overall, likely from lower socioeconomic backgrounds. Of the evaluation participants who indicated their gender, 84% were women.

Analysis of the second pilot's pre/post knowledge questionnaires showed that for the FHH questions, the percent of respondents answering correctly essentially stayed the same (i.e., at over 90% correct at both timepoints) for four of the five questions, but increased for the fifth. When only those who provided complete pre and post FHH data were included in the analyses, neither the group as a whole nor particular age or educational subgroups showed a statistically significant increase in the overall FHH knowledge score.¹² For the RGH questions, the percent of respondents answering correctly increased from pre-test to post-test for three questions, stayed essentially the same (i.e., close to 100% at both timepoints) for one question, and demonstrated a small decline for one question. The most notable increase in percent correct (39% to 75%) occurred for the yes/no item: "The genes of all people are 99.9% the same regardless of ethnic or 'racial' identity." When considered as a group, all participants who provided complete pre and post RGH data showed statistically significant RGH knowledge score increases, as did age and educational subgroupings of participants. It should be noted, however, that rates of missing values for the individual knowledge items were high (higher than in the first pilot, at 16-26% across FHH and RGH data)—and missing rates were even higher when items were aggregated to calculate mean scores and demographic characteristics were taken into account. The findings should therefore be interpreted with due caution.

¹² It should be noted that the statistical methods used to analyze knowledge change over time questions differed from Pilot 1 to Pilot 2, so findings from the two pilots are not directly comparable.

As in the case of the first pilot, the vast majority of workshop participants rated the workshop content, delivery, and materials (including the booklets) very highly. Suggestions for improvement included making the presentation longer and having less paperwork during the presentation.

Of the 183 evaluation participants, 84% pledged in writing to engage in one of three health-related behaviors during the two months post workshop (i.e., collect family health history, engage in positive lifestyle choices related to diet, engage in positive lifestyle choices related to physical activity). The most common pledge (as in pilot 1) was to discuss family health history with family members. Two-month follow-up interviews revealed that of the 153 participants who had made a pledge, 50% reported achieving their pledge, 22% reported not achieving their pledge, and 27% did not provide follow-up data (i.e., the phone number they had provided was disconnected or they did not respond to the follow-up call). A sizable minority of those who had made a pledge reported engaging in more than one of the pledge list behaviors during the follow-up period. These findings are similar to those of the first pilot (see above).

Additional analyses of the pledge data assessed movement along five stages of change for the behaviors pledged to and not pledged to. For *all behaviors, whether pledged to or not pledged to*, there was an increase in the percent of evaluation participants at the maintenance stage, which was the highest stage considered in the analysis. This was an encouraging behavioral finding. However, among those who pledged to collect family health information, there was also an increase in the percentage of participants at the precontemplation stage, which was the lowest stage considered in the analysis. Moreover, among those who did *not* pledge to engage in positive lifestyle choices related to diet, there was also an increase in the percentage of participants at the precontemplation stage for this behavior; similarly, among those who did *not* pledge to engage in positive lifestyle choices related to physical activity, there was an increase in the percentage of participants at the precontemplation stage for this behavior. It should be noted that rates of missing data were high in the stages of change analysis, because only participants who provided data at both timepoints (i.e., immediately post-workshop and at two-month follow-up) could be included; moreover, tests of statistical significance were not performed on the stages of change data.

b. Limitations

Key methodological challenges of pilot 1 and difficulties interpreting the data were summarized above. Pilot 2 addressed a number of those concerns successfully by standardizing workshop content and length, conducting all workshops in the targeted wards, and incorporating a stages of behavior change analysis. However, the relatively high rate of missing knowledge data across both pilot studies raised some concerns about the internal validity of the findings. Additionally, in pilot 2, those who completed the FHH knowledge questionnaire were already close to ceiling at pre-test, with over 90% correct for each item. This limited the opportunity for participants to show improvement as a result of intervention participation.

Moreover, in addition to also having a relatively high rate of missing data, the pilot 2 stages of change analyses had several other important limitations. In particular, the three health-related

behaviors that were measured differ in some important ways. First, collecting family health history requires cooperation of others, while engaging in positive diet and physical activity does not (among adults). Second, collecting family health history is a circumscribed activity, which means that once done, it need only be revisited periodically. On the other hand, when diet or physical activity is altered, the new behaviors need to be maintained on an ongoing basis to make a difference. Another limitation of the pilot 2 stages of change analysis is that no data were collected on the quality, degree, or completeness of the three health-related behaviors participants engaged in. For example, a workshop participant could have collected partial or complete family health history information, and a participant who reported engaging in positive changes related to diet may have modified his or her diet in a limited way or a radical way. Finally, due to project time constraints, only limited analyses were performed on the stages of change data. It is not known whether workshop participants as a group moved up or down the stages of change for particular behaviors pledged to or not pledged to, and whether such movement was statistically significant.

Several additional limitations of both pilot studies should also be noted. The majority of the participants from both pilots were older African American women, limiting the generalizability of the findings to other groups of African Americans. In addition, behavioral data were collected via self-report, which is subject to social desirability bias, over a relatively short period only (i.e., two months). Finally, without a comparison group, and without a robust literature on pledge completion rates, it is difficult to assess the relative effectiveness of the community workshops in changing behavior.

c. Discussion and implications of findings

Over the course of both pilots, the Howard team worked to streamline evaluation processes, standardize workshop content and length, and increase participation of community members residing in the targeted wards. Howard showed notable successes in improving consistency of workshop delivery and in reaching targeted ward residents. Different incentives for evaluation participation (e.g., giftcards) might have helped to reduce missing data—however, monetary incentives for pre/post evaluation participation had been ruled out by Howard’s IRB, which considered them to be potentially coercive.

In spite of the data limitations described above, the impact of the intervention on knowledge of race, genetics, and health, in particular, seems robust. In addition, it is clear that participants responded very favorably to the workshop content and materials. The pledge component seems promising as well, but additional research is needed to shed further light on its impact. For example, a mixed-method (quantitative/qualitative) study might compare the behavioral outcomes of different intervention conditions, such as a workshop without a pledge, a workshop with a pledge, and distribution of booklets coupled with a pledge. Further analysis of the existing stages of change data, including assessment of whether the group moved up or down along the stages, and whether these changes were statistically significant, would also be a fruitful next step in the research.

VI.C.2. Website

From December 2007-May 2010, visitors to Howard's CGEN website submitted a total of ten inquiries and 13 website feedback questionnaires, and 164 people joined the mailing list. A number of the inquiries concerned genetic testing for ancestry. The majority of the questionnaires were submitted by African Americans; they were of diverse ages and resided in a variety of geographic areas. Collectively, visitors who completed questionnaires had come to the website through a multiple sources, such as a Google search, referral by someone at Howard, or a link from another website. Most reported finding the website to be useful or very useful. Those who requested to join the mailing list hailed from 26 states, the District of Columbia, Mexico, and the Virgin Islands. The largest number of mailing list registrants resided in Texas and in New York (13 each). The ages of those who joined the mailing list ranged from 15 (the age requirement was later raised to 18) to 92. As of May 2010, the only notification that had been sent to the mailing list was an invitation to Howard's CGEN-related Town Hall Meeting (held in May 2009).

Overall, the level of website utilization is unclear, as the Webmaster did not collect data on number of website hits, page views, or visitors. The project coordinator has made some updates to the site, plans additional updates, and would like to get additional input from consumers on how to make the site more useful and appealing. The two-month follow-up interviews from the second community workshop pilot (conducted in summer 2010) included a reminder to participants about the website. Interviewees were also asked if they had used the website after the community workshop; nine respondents (about 8%) indicated that they had.

VI.C.3. Toll-free Number

From December 2007-May 2010, the toll-free number received a total of 21 messages, of which 16 were wrong numbers (i.e., callers were attempting to call dentistry services at Howard). Collectively, the five calls that were not wrong numbers requested information on family health history, genetics and ancestry testing, and copies of the family health history tree insert for an upcoming family reunion.

The toll-free number has been extremely underutilized, despite being publicized at community workshops and in Howard CGEN materials. The two-month follow-up interviewee from the second community workshop pilot included a reminder about the number. Staff are assessing whether to change the number (due to the many wrong-number calls) and whether to continue to support a toll-free number at all.

VI.D. Utah

As was discussed above (see Section V.B.4), Utah's local evaluator conducted process evaluation and a pre/post outcome evaluation of Utah's three interventions: fifth grade curriculum and materials, secondary school materials, and community workshops. The findings, limitations, and implications are summarized below.

VI.D.1 Fifth Grade Curriculum and Materials

a. Findings

The fifth grade pilot study targeted four teachers and 100 students, but ultimately six teachers and 178 students participated in the intervention. Of the 178 students, 159 provided matched pre/post surveys, and 169 completed post-test satisfaction questions. The students were not asked to indicate their ethnicity, but approximately 49% indicated that they spoke either English and Spanish, or Spanish only, at home. The student pre/post data showed statistically significant increases in genetics knowledge and confidence in that knowledge; missing data rates for these items were very low. The post-test data also showed that the students enjoyed the activities, shared the materials with their families, and would like to learn more about genetics. The teacher surveys indicated that the material was culturally appropriate, the reading levels were appropriate, and the material was effective and engaging to students. Teachers also indicated that they would definitely use the materials again in the future. They were especially positive about the fact that students used the materials at home with their families, and that the Spanish-language materials engaged parents who otherwise might not have been able to participate. Teachers felt this was beneficial to both parents and students, and indicated that parents commented favorably on the materials in parent-teacher conferences.

Teachers had very few criticisms of the materials, although they made a number of useful suggestions for improvement, including:

- Provide an introductory letter for parents explaining the concepts and the vocabulary;
- Put Spanish and English on the same page or on the front and back of the same page;
- Minimize the amount of materials families need to have at home to participate in the activities;
- Add some exercises that allow students to practice key mathematics concepts; and
- Link heredity and genetics in humans to heredity and genetics in plants and animals.

Utah made a number of revisions to the materials in light of the feedback.

It should be noted that since the formal evaluation was completed, the GSLC has received feedback from the teachers that they continue to use the materials every year, and that use of the materials has spread throughout the Salt Lake City School District, so that most fifth grade teachers are now using them. Informal feedback from teachers (at conferences, workshops, and meetings, as well as via website feedback) also indicates that the materials are being widely used by fifth grade and middle school teachers throughout Utah and across the U.S.

b. Limitations

The fifth grade pilot study had several key limitations. With respect to the teachers, the sample size was very small, potentially limiting the generalizability of the results. Additionally, none of the teachers was Hispanic/Latino, and so they could not provide feedback as members of the targeted ethnic group. Also, the student evaluation included only short-term follow-up; as such, it was not possible to measure maintenance of short-term changes over time, or longer-term behavioral changes, for which inclusion of a comparison group would have strengthened evidence for a causal link between the intervention and changes reported by students. Moreover,

attendance of evaluation participants was not tracked, so precise levels of exposure to the intervention are not known. However, given the relatively large sample size, it is unlikely that variable attendance levels had much of an impact on the findings. Finally, although the take-home family materials were an important component of the curriculum, there was no direct or systematic assessment of satisfaction or outcomes among students' family members.

c. Discussion and implications of findings

The fifth grade pilot study provided compelling evidence that the intervention achieved its short-term objectives. The involvement of students' families in the intervention, through the use of linguistically and culturally appropriate materials, is a particularly interesting component that is worthy of further investigation. Future research might involve parents as subjects—to assess systematically their perceptions of the materials, as well as changes in relevant knowledge, attitudes, and behaviors.

VI.D.2. Secondary School Materials

a. Findings

The secondary school pilot study targeted six teachers and 420 students, but ultimately six teachers and 498 students participated in the intervention. About 53% of student participants reported being Hispanic or Latino. The student pre/post survey data indicated that genetics knowledge increased significantly, as did student confidence in their knowledge. The increases in knowledge and confidence did not differ according to whether students saw the bilingual video. Analysis of the knowledge questions by demographics showed that junior high students made significant knowledge improvements from pre-test to post-test, but senior high students did not. (The lack of significant improvement among the latter may be due to a ceiling effect; see below.) Senior high students got more answers correct and were more confident in their answers if they were not Hispanic/Latino, while junior high students did not show such differences based on ethnicity.

The post-test data showed that most students talked about their family health history (FHH) with at least one family member, and the majority worked on their FHH homework assignment with at least one family member. Students were significantly more likely to have both talked to and worked with at least one family member on FHH if they were in classes that saw the video. Additionally, among students who had not completed the FHH assignment by post-test, those who had seen the video were more likely to report the intention to complete a FHH than those who had not seen the video. Most students also indicated at post-test they would definitely or probably like to learn more about using FHH to improve their health; there was no difference in interest based on whether students saw the video. In general, in the post-test satisfaction data, there was little consistent negative feedback from students. A small percentage did not like the extra work or did not like the material, but the majority liked the activities, the video, and the FHH take-home assignment.

The teacher survey data showed that five of the six teachers liked the video as an introduction to the material and an additional mode of instruction for the unit. Teachers assessed the other in-

class materials and the take-home materials very favorably as well and indicated that they would use the materials again in the future. Teachers did not feel that there was a big difference in interest level among students who saw vs. did not see the video. However, as indicated above, analyses of the survey data indicated that the video condition was significantly correlated with students working on the FHH, completing it, and planning to complete it if they had not done so already.

Overall, teachers had no substantive recommendations for changes to the written materials. For the video, teachers recommended including larger subtitles, showing more cultural diversity among the students, and discussing more diseases and possibly more detail about those diseases. Two teachers felt that the video did not need to have depictions of the activities that were going to be done in the class. Edits were not made to the video, due to the cost involved.

b. Limitations

The secondary school pilot study had several key limitations. With respect to the teachers, the sample size was very small, potentially limiting the generalizability of the results. Additionally, none of the teachers was Hispanic/Latino, and so they could not provide feedback as members of the targeted ethnic group. Also, the teachers did not provide extensive feedback in response to the open-ended questions the way the teachers did for the elementary school materials.

In addition, the student evaluation included only short-term follow-up; as such, it was not possible to measure maintenance of short-term changes over time, or longer-term behavioral changes, for which inclusion of a comparison group would have strengthened evidence for a causal link between the intervention and changes reported by students. Also, evaluation participants' attendance was not tracked, so precise levels of exposure to the intervention are not known. However, given the relatively large sample size, it is unlikely that variable attendance levels had much of an impact on the findings. Additionally, neither students nor classes were randomly assigned to the video vs. non-video conditions; instead, the teachers chose which classes would receive which conditions. It is possible that this introduced some bias, although there is no specific evidence of bias. Also, because there were multiple demographic variables of interest and two class conditions, the number of participants in each cell was highly variable (and sometimes very small), when all variables were included, limiting the validity and generalizability of the findings for particular demographic groups. It should also be noted that as in the case of the fifth grade pilot study, although the take-home family materials were an important component of the curriculum, there was no direct assessment of satisfaction or outcomes among students' family members.

As was indicated above, another limitation was that there may have been a ceiling effect for the knowledge questions for the high school students. If Utah had had statewide tests for health education classes, it might have been possible to compare student performance on state standards for this unit; however, no such statewide tests for health education classes exist.

Finally, the video appeared to increase the completion of the FHH assignment, but the mechanism for this effect is unclear. It does not appear to be due to increased interest in or knowledge of FHH, as the group that saw the video did not show greater interest or knowledge at

post-test than the group that did not see the video. Perhaps the video communicated that FHH was important, and/or it normalized the process of obtaining FHH information by portraying actual students who were similar to pilot study students.

c. Discussion and implications of findings

The secondary school pilot study provided compelling evidence that the intervention achieved its short-term objectives. Moreover, regardless of the mechanism of action, the video did appear to increase completion of the FHH homework assignment, and intention to collect FHH information among students who had not completed the assignment as of the end of the data collection period. Therefore, the local evaluator has recommended that the video continue to be included in the intervention. As in the case of the fifth grade intervention, future research on the secondary school intervention might involve parents as subjects—to assess systematically their perceptions of the materials, as well as changes in relevant knowledge, attitudes, and behaviors.

VI.D.3. Community Workshops

a. Findings

A total of eight community workshops were delivered in community centers and churches over the period July 2009-January 2010, reaching 97 adults (essentially achieving the target of 100). Of these adults, 97 participated in the evaluation and 95 provided matched pre/post test surveys. The 95 matched surveys constituted the sample for the evaluation analyses. Overall, rates of missing data were low. About 93% of participants reported being Tongan; one participant reported being Samoan; and the rest self-identified as Other (including but not limited to White). About 42% of evaluation participants were male, which was a much higher percent than in other CGEN community workshops (i.e., for other community workshop interventions, males comprised less than 30%—and in some cases less than 20%—of study participants; see also Section VI.E.1). Anecdotally, it was reported by the instructor that some men were prompted to attend the workshop by loss of a friend to a genetically-linked illness. However, when later asked about the relatively high rate of male attendance, the instructor attributed it to the fact that the workshops were held in locations and at times when men were normally present (e.g., at church on Sunday or at senior centers during a standard class time). Several of the workshops were held as part of a six-week class on chronic disease in which men were participating.

Analysis of the pre/post data showed that knowledge (i.e., of inherited traits and diseases, what it means to be at low or high risk for a disease, and how diet and exercise can mitigate the effects of genetic risk) and confidence in that knowledge increased significantly. Males and older participants started out with slightly lower levels of knowledge than females and younger participants (respectively) but made greater gains in knowledge. Participants with higher levels of acculturation exhibited higher knowledge at both pre- and post-test than participants with lower acculturation. Additional analyses of the relationships between specific demographic characteristics and knowledge and confidence-in-knowledge outcomes are difficult to interpret, given the small sample sizes involved. With respect to the belief that healthy diet and exercise could reduce the chance of getting an inherited diseases, participants were essentially at ceiling at pre-test and showed no significant change at post-test.

At post-test, the majority of participants agreed that they would like to learn more about inherited traits and diseases, that they would talk about family health history (FHH) with their families, that they would collect FHH, and that they would make lifestyle changes based on what they had learned. Overall, participants had positive feedback on the workshop; the most common response to what they liked least or what could be improved, other than that they liked everything, was that they did not like taking the surveys.

A key theme that emerged from the formal evaluation and from anecdotes from the instructor was that the intervention content seemed to have the greatest impact when it was taught in a way that was maximally relevant to participants and to their community, so that they could personalize the information. The instructor provided details on the top causes of death among Pacific Islanders, and the high prevalence of diseases like diabetes among Pacific Islanders in Utah, and she spoke about Tongan customs concerning consumption of unhealthy foods. Participants spoke emotionally about poor health habits that they have passed down to their children and grandchildren. Although at pre-test participants already believed that diet and exercise could impact disease, many noted at post-test that one thing that they had learned was that they could impact their health, even if they were at high risk for inheriting a disease, and the majority reported that they planned to make positive lifestyle changes based on what they had learned from the class. While this could reflect a positive response bias, it may also mean that as a result of the class they were treating the link between diet/exercise and health more seriously.

b. Limitations

The Tongan pilot study included only a pre and immediate post-test; as such, it was not possible to measure maintenance of short-term changes over time, or longer-term behavioral changes (for which inclusion of a comparison group would have strengthened evidence for a causal link between the intervention and changes reported by participants). In addition, the survey instruments were very brief, in order to ensure that there would be sufficient time for the intervention. Some questions may not have been sensitive enough (e.g., belief question) to show variation among participants from pre- to post-test. Also, the relatively small sample size prevented more robust analyses of differences across demographic groups within the sample. Moreover, participants' open-ended comments were brief, likely due to the combination of limited time for completing forms and limited literacy skills; cultural factors influencing attitudes toward putting comments in writing may have also come into play. Focus groups or interviews (i.e., oral feedback channels) might have yielded richer participant feedback. Additionally, because the instructor did not complete an implementation survey or checklist, it is not known to what extent the material was delivered consistently across sessions. Finally, the only instructor was also one of the developers of the materials. Although she provided feedback on the materials throughout the development process, the pilot study did not yield the same kind of more objective instructor feedback that would have been obtained if the materials had been taught and assessed by multiple instructors who had not been part of the development process.

c. Discussion and implications of findings

As was indicated above, making health information personally relevant to participants, their families, and their community seemed to be a particularly crucial aspect of this intervention. Indeed, the importance of helping participants in health prevention and promotion programs to personalize intervention content has been noted as a best practice in the literature on use of family health history to promote healthy lifestyles and disease prevention (Claassen et al., 2010) and in a number of other health promotion and prevention areas (e.g., teen pregnancy prevention—see Kirby et al., 2005; smoking cessation—see Bock et al., 2008). Emphasizing the importance of modeling healthy behavior for other family members and the younger generation may also be particularly important in cultural contexts that place high value on family relationships and intergenerational learning.

The instructor who delivered the community workshop had contributed robustly to its development and was a well-known and well-respected leader in Utah's Tongan-American community. Future research on this intervention might fruitfully investigate factors that contribute to the successful replication of the workshop with Tongan-Americans and/or Tongans in Tonga, when it is delivered by other instructors. Future research might also include longer-term follow-up with participants (using structured or semi-structured interviews) to assess behavioral change.

VI.E. Selected Cross-Site Comparisons

As was discussed above in Section V.A.3, early plans to establish a set of common cross-site indicators and instruments were abandoned in late 2007. This made it difficult to “sum up” the collective reach and impact of the CGEN interventions. Recently, March of Dimes staff made an effort to collate responses to similar survey items across sites. Available data related to one output (gender of participants) and one outcome (knowledge of where genes come from) are discussed below, as they provide insight into some of the successes and challenges of the CGEN educational efforts.

VI.E.1. Gender of Participants

Cross-site data on the gender of evaluation participants are provided in Table 7, below. As is seen in the table, females and males each constituted approximately half of the sample in Utah's school-based program pilot studies, which had “captive” student audiences. CBWCHC's pre-counseling workshops targeted pregnant women, so the 100% female participation rate in the treatment and control groups was expected. (It should also be noted that women who participated in the pre-counseling workshops were told that their partner could participate in the workshop, if desired; however, no partners participated.) Among the interventions that targeted both males and females and had voluntary participation, the percentage of males was relatively low, ranging from only 10% for the CHW trainings to 42% for Utah's community workshops for the Tongan population. These findings highlight the challenge of reaching males with genetics education interventions.

Table 7. Cross-Site Comparison: Gender of Evaluation Participants^{1,2}

	CBWCHC				DWDC								Howard				Utah					
	Pre-Couns. Workshop, Treatment Group		Evaluation Control Group		CHW Trainings ³		Commun. Workshop 1 (Main)		Commun. Workshop 2 (Main)		Commun. Workshop 2 (Pregnancy)		Commun. Workshop 1		Commun. Workshop 2		Fifth Grade		Secondary School		Tongan Commun. Workshop	
	<i>N=44 Missing=0</i>		<i>N=42 Missing=0</i>		<i>N=21 Missing=0</i>		<i>N=114 Missing=5</i>		<i>N=133 Missing=5</i>		<i>N=90 Missing=4</i>		<i>N=178 Missing=20</i>		<i>N=183 Missing=29</i>		<i>N=159 Missing=0</i>		<i>N=404 Missing=2</i>		<i>N=95 Missing=0</i>	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Female	44	100	42	100	19	91	90	83	110	86	75	87	117	74	129	84	81	51	209	52	55	58
Male	0	0	0	0	2	10	19	17	18	14	11	13	41	26	25	16	78	49	193	48	40	42
Total	44	100	42	100	21	101	109	100	128	100	86	100	158	100	154	100	159	100	402	100	95	100

Notes:

¹ For cross-site comparison purposes, missing data have been *excluded* from the calculation of n's and percentages.

² Total percentages do not always add up to exactly 100% because of rounding.

³ Of the 21 CHWs who participated in any CHW training sessions, only seven—all women—delivered community workshops.

VI.E.2. Knowledge of Source of Genes

Cross-site data on knowledge of whom people get their genes from are summarized in Table 8, for those local evaluation studies that included a pre/post survey question on this topic. Although the survey questions on this topic were not identical across sites, it is clear from the findings that among some groups, there was relatively low understanding of the source of genes prior to participation in the CGEN intervention. At the same time, however, among groups in which under 90% of respondents had correct information prior to intervention, there was notable improvement from pre-test to post-test (e.g., 75% to 92% correct DWDC’s pilot 2 community workshop participants, 58% to 87% correct among Utah fifth graders, and 45% to 77% correct among Utah community workshop participants). These findings highlight the need for basic genetics education and the opportunity to improve knowledge through brief interventions. At the same time, the fact that no group scored 100% (or even close to 100%) on this item underscores the challenges of improving knowledge about even the most basic concepts in genetics.

Table 8. Cross-Site Comparison: Knowledge of Source of Genes

Site, Intervention, and Knowledge Question ¹	N and Missing n	Correct Responses			
		Pre		Post	
		n	%	n	%
<u>DWDC Community Workshop, Pilot 1</u> We get all of our genes from our mother and none from our father. (True/False/Don’t Know)	N=114, Missing=0	82	72	95	83
<u>DWDC Community Workshop, Pilot 2</u> We get all of our genes from our mother and none from our father. (True/False/Don’t Know)	N=133 Missing=2	98	75	120	92
<u>Howard Community Workshop, Pilot 1</u> We get all of our genes from our mother and none from our father. (True/False)	N=178, Missing=29	142	95	132	89
<u>Howard Community Workshop, Pilot 2</u> You get all of your genes from our mother and none from our father. (Yes/No)	N=183, Missing=34	138	93	138	93
<u>Utah Fifth Grade</u> If you are a boy, you will get most of your inherited traits from your dad. If you are a girl, you will get most of your inherited traits from your mom. (True/False)	N=159 ²	92	58	139	87
<u>Utah Tongan Community Workshop</u> If you are male, you will get most of your inherited traits from your father. (True/False)	N=95, Missing=1	42	45	72	77

Notes:

¹ In each row, all answer choices are listed; correct choice is boldfaced.

² Missing values, which were few, were treated as “incorrect” for purposes of the knowledge analyses.

VI.F. Discussion of Findings

Overall, across the CGEN interventions, evaluation participation rates were generally high, and most sites had relatively low rates of missing data. Many pilot evaluations had largely positive process evaluation findings; they showed that sites had essentially delivered the intended services, activities, or materials to the targeted racial or ethnic and geographic groups and for the most part had reached the targeted number of participants. Participant feedback on the interventions and materials was overwhelmingly positive and often included some helpful suggestions for improvement. A number of the training/educational workshops did experience some difficulty delivering workshop content consistently. Shorter-than-intended workshop slots, diverse baseline knowledge and interests among participants, and the need for time to complete evaluation-related procedures presented particular challenges. Additional training for workshop facilitators appeared to help address these challenges. One site also experienced particular difficulty reaching the intended target population in an initial pilot study; closer collaboration with CAB members, the local March of Dimes Chapter, and other local agencies helped to ensure greater participation of the targeted population in a second pilot study.

CBWCHC was the only site that specifically targeted a particular gender group (i.e., women). Among the other groups, there were no specific gender-related targets, but participation by gender was worthy of examination. Utah's school-based interventions had "captive" student audiences and reached approximately equal percentages of boys and girls. Among the other interventions, recruitment efforts targeted both genders; however, rates of male participation were for the most part low. The intervention that reached the highest percentage of voluntarily participating males was Utah's Tongan community workshop; the most plausible explanation for the relatively high participation is that the workshop was delivered in locations and at times in which men were already present (e.g., churches, senior centers). No site undertook a specific, tailored effort to reach out to men; such an approach might have helped to increase male participation.

In accordance with the overall CGEN logic model (see Figure 1 in Section I, above) and the local logic models, all of the sites demonstrated at least some positive, short-term changes in participants' knowledge and/or other behavioral determinants, such as interest in learning more about genetics or intentions to discuss family health history with family members and/or health care providers. No site documented any statistically significant negative changes in participant outcomes.

As was discussed above, knowledge of the sources of genes was addressed and assessed by a number of the Phase II pilot projects. It is interesting to note that in many populations, a relatively low percentage of participants had accurate knowledge prior to intervention participation. For these populations, knowledge of this topic tended to improve considerably after intervention participation; however, scores did not reach 100% (or close to it). This pattern is common across a number of other knowledge items (data not shown above), supporting the point made in the scientific literature that while brief educational interventions can improve knowledge, changing even basic genetic knowledge among everyone in a group is challenging, given abstract nature of the material, different individual learning styles, and the persistence of

cultural norms and beliefs that may be at odds with scientific principles of genetics (Barlow-Stewart et al., 2006; Barlow-Stewart, 2007).

Among the common outcome study limitations across many CGEN interventions were lack of mid-term or longer-term follow-up and lack of a comparison group, which limited or precluded measurement of whether short-term changes in behavioral determinants were sustained, and whether behavioral changes were achieved. These are common limitations among community-based, “real world” evaluations that have modest evaluation budgets.

Overall, the available quantitative and qualitative data suggest that all of the sites showed considerable success in making genetics more accessible, appealing, and relevant to members of underserved ethnic and racial minority communities, through the development and implementation (or deployment) of culturally and linguistically appropriate interventions and materials. A focus on the importance of lifestyle (especially diet and physical activity) for mitigating the expression of genetically linked diseases was a common theme across many of the interventions. Family health history also emerged as a common theme and appeared to help participants to personalize the educational content. Together, these themes may ultimately help foster sustained, desirable behavioral changes, which across the local CGEN interventions include informed health decision-making, consultation with family and health care providers about genetics and health, use of genetics services among high-risk populations, and adoption of lifestyle changes to reduce genetic-based health risks.

VII. Dissemination of Evaluation Findings and Solicitation of Feedback

As of the writing of this report, Phase II findings and lessons learned had been shared in a variety of ways within the CGEN team, with local site stakeholders, and with the broader field.

VII.A. Within the CGEN Team

During the five-year project period, periodic evaluator conference calls, in-person meetings, all-team quarterly conference calls, and more informal calls and email served as venues for the discussion of evaluation findings, including analysis methods, data interpretation, and data presentation. These discussions benefited local and national evaluators alike and facilitated the sharing of best practices across sites—for example, concerning methods for treating missing data and visually displaying data. Overall, all parties endeavored to respect the autonomy of local evaluators, while incorporating the insight and experience of other local project team members and acknowledging the advisory and oversight roles of the national evaluators and March of Dimes project staff.

VII.B. With Local Stakeholders

Solicitation of feedback from local stakeholders is a crucial component of a CBPR approach. Specifically, it can increase the validity and authenticity of the findings, build community trust, and help ensure that findings are used appropriately and to the benefit of the community (Cashman et al., 2008; Thompson-Robinson et al., 2004). As of the writing of this report, local site evaluation findings had been shared with local stakeholders in a number of ways:

- Throughout Phase II, CBWCHC reported on evaluation progress and findings to their Women's Health Advisory Committee, which was also their CAB. The Women's Health Advisory Committee is a group of representatives from various community organizations who help CBWCHC to improve their services. CBWCHC also brought information back to the community at a Women's Health Symposium held in June 2010 in partnership with the Center for the Study of Asian American Health at the New York University School of Medicine.
- DWDC shared and discussed some of the community workshop pilot findings with the CHWs. In addition, on June 30, 2010 they delivered a local press conference on the project's overall evaluation findings; 70 people (60 adults and 10 children) attended, including one of DWDC's CGEN CHWs. An article on the project was subsequently published in Spanish in the newspaper *El Nacional*, and a story about the project was featured on cable television channel Manhattan Neighborhood Network. DWDC also reported having plans to post a summary of the evaluation findings on their website, although as of the finalization of this report findings had not yet been posted.
- At the completion of their first and second pilot studies, Howard shared their findings with their CAB, which offered insights concerning interpretation of the data and suggestions for how to sustain successful aspects of the project. In addition, Howard sent a letter with a brief summary of the short-term project findings to participants in the second pilot study who completed the two-month follow up phone interview. (The letter with summary was included with the incentive giftcard that was provided to participants who were interviewed.) Howard

also reported having plans to post a summary of the evaluation findings on their website, although as of the finalization of this report findings had not yet been posted.

- Utah shared its school-based findings with the respective school districts and principals. They did not receive any feedback from these parties, but they have found that many of the fifth grade teachers in the Salt Lake City School District are now using the materials. Utah also shared an executive summary of the school-based findings with the Hispanic/Latino CAB and emailed the members copies of the full reports. The NTAS has shared the Tongan community workshop evaluation report with the Tongan/Pacific Islander CAB and reported having plans to provide copies of the report at churches where the classes were held.

VII.C. Among the Broader Field and the Public

A number of the CGEN sites have presented evaluation findings at professional conferences. For example, Howard presented some findings from its first community workshop pilot at the NIH Summit on the Science of Eliminating Health Disparities in December 2008. CBWCHC and Utah presented findings at the New England Regional Minority Health Conference in October 2009. Utah also presented at the American Society for Human Genetics in October 2009, and CBWCHC presented findings on an Association of Asian Pacific Community Health Centers (AAPCHO) webinar in May 2010. CBWCHC, Howard, Utah, and the national evaluation team presented evaluation findings in an oral session at the APHA Annual Meeting in November 2009, and the March of Dimes presented a poster that included a summary of selected CGEN evaluation findings at the APHA meeting in November 2010. Utah also regularly shares the school-based outcomes with teachers who participate in workshops on the fifth grade and secondary school materials at local, regional, and national science education conferences. Replication toolkits for the CBWCHC, DWDC, and Howard CGEN interventions, which had been completed as of the writing of this report, each include a summary of the respective site's evaluation findings.

Sharing of evaluation findings with the general public (locally or nationally) has to date been very limited. As was indicated above, DWDC recently presented its findings at a local press conference (June 2010). Two of the sites reported plans to post a summary of their evaluation findings on their websites, but as of the finalization of this report had not yet done so. March of Dimes brought a consultant editor and writer to the in-person CGEN meeting in May 2010 to discuss opportunities to share information about CGEN through popular media, to reach the lay community; however, as of the finalization of this report, the March of Dimes has no plans to share evaluation findings, specifically, with the general public.

VIII. Additional Phase II Outcomes

Project outcomes among CGEN local sites, their staff, and other community partners were not measured formally in Phase II. However, a review of local reports and meeting minutes and more informal discussion among the CGEN team indicated that the project did achieve some additional outcomes among these stakeholders. In particular:

- CBWCHC program staff learned about important aspects of evaluation, such as the utility of including a control group and potential sources of bias in a dataset. CBWCHC evaluation staff, meanwhile, learned additional strategies for increasing survey response rates. The organization as a whole became more aware of the time involved in working with an external IRB, and in response developed procedures for assessing future research participation opportunities from a more strategic perspective. Additionally, CBWCHC applied the replication toolkit concept (used in Phase II to support Phase III dissemination activities) to its cervical cancer screening efforts.
- Community members trained by DWDC to serve as CHWs expanded their presentation and facilitation skills. As was discussed in Section VI.B.1.a, some of these CHWs have gone on to work as CHWs or other health information brokers in other community settings.
- The Utah site built new connections with diverse cultural groups in the Salt Lake City area. A particularly noteworthy development is that although the site tried unsuccessfully to partner with local Native American communities early on in the CGEN project, toward the end of the project two Native American community organizations collaborated with the GSLC on another genetics and health education effort, which is supported by the National Institutes of Health (NIH) National Human Genome Research Institute and the University of Utah Center for Clinical and Translational Science. The GSLC also continued its collaboration with the National Tongan American Society by partnering with them on this same project. Overall, materials developed for the CGEN project have been used in educational programs with the Native American, African refugee, African American, Chinese, Hispanic/Latino, and Tongan communities.
- A total of 15 graduate students in Howard's Genetic Counseling Training Program served as volunteer assistants for Howard's community workshops. In addition to helping the CGEN program, they derived valuable real-world experience interacting with community members around issues of genetics and health. Graduate student volunteers also gained evaluation-related experience by assisting with data collection activities during the workshops and by working with the local evaluator to complete the two-month follow-up interviews.

All of the CGEN partners—local and national—reported gaining greater experience with CBPR; improving their ability to address issues of cultural and linguistic competence; expanding or strengthening their relationships with (other) community agencies; increasing their capacity to make genetics and health information accessible to underserved and low-literacy communities; and learning how to better evaluate and disseminate their project materials and findings. Anecdotally, several team members also reported that their participation in CGEN has had an impact on their own health-related behaviors.

Cross-site communication was a particularly important vehicle for achieving these outcomes. In particular, local site staff, local evaluators, national evaluators, March of Dimes project staff, and the HRSA Project Officer shared educational materials, evaluation tools, program implementation and evaluation techniques, and dissemination opportunities with each other through conference calls, in-person meetings, email, and the shared online workspace that March of Dimes made available to the project team. Sites learned from each other and then selected, adapted, and applied those items that fit their needs. For example, genetics-related learning games for general audiences developed by Utah were used by two other sites at local health fairs. Color-coding of evaluation forms was discussed among the evaluators and widely applied as a simple technique for improving the efficiency and validity of evaluation procedures.

Collectively, over the Phase II period, these outcomes increased the capacity of the CGEN partner agencies, their staff, and their community partners to address the health-related needs of community members. This in turn has advanced the ultimate CGEN goal of decreasing health disparities.

IX. Discussion of Challenges and Lessons Learned

The CGEN team experienced a number of implementation and evaluation-related challenges, and learned many associated lessons. Key challenges and lessons are summarized briefly below.

IX.A. Reaching the Intended Populations

Overall, sites were able to reach the intended racial/ethnic and/or geographic groups and to meet their targets for number of community participants. These accomplishments often required collaboration with other community partners. Although most sites did not set specific participant targets by gender, the general finding was that women were far more likely to participate in voluntary interventions than men. This finding raises questions about how best to involve men in genetics education efforts.

IX.A.1. Securing Participation of the Targeted Racial/Ethnic and Geographic Groups

a. Challenges

Genetics is not the most common issue on the minds of most people, nor is it the most accessible. Given these factors, all of the sites had to consider how best to encourage participation in their interventions and evaluations. One of Utah’s strategies was to develop materials for “captive audiences” of school students, and to ensure that these materials addressed relevant science and health education standards, to increase appeal to schools and teachers. Utah also created materials that would permit Hispanic/Latino parents—who were often excluded from participation in many of their children’s educational activities by language or literacy barriers—to be involved in the learning process with their children, through accessible homework assignments. CBWCHC and DCWC, as community-based organizations, leveraged their existing reputations as trusted local service providers to promote intervention and evaluation participation by local community members. In addition, all four sites also leveraged existing—and/or built new—relationships with other partners or collaborators who were seen as trusted sources of information and services in their respective local communities. For some of the sites, CAB members’ connections were very helpful in this regard, and for one site the local March of Dimes chapter also provided assistance.

Although all sites were able to reach their overall target numbers for their major interventions, one site did experience difficulty, particularly in its first workshop pilot study, in reaching the intended geographically-based population. A couple of sites experienced some challenges with maintaining intervention participation and/or with achieving consistent evaluation participation.

b. Lessons

Fostering positive relationships with trusted, on-the-ground partners is often essential to reaching the intended community participants, particularly when the lead agency is not itself a community-based organization. Clearly delineating responsibilities and timelines and providing stipends to partner agencies for their involvement can help avoid misunderstandings, build good will, and foster a sense of responsibility and commitment.

Additionally, offering concrete incentives (such as stipends, gift cards, or public transportation tickets) can increase intervention and evaluation participation. It is important to ensure that incentives are culturally, geographically, and age-level appropriate, and that they do not constitute coercion or place undue pressure on potential participants.

IX.A.2. Reaching Both Males and Females

a. Challenges

As was discussed above, among the interventions that sought to recruit voluntary male and female participants, male participation rates tended to be low (i.e., 10-42% of participants). No site applied specialized or targeted strategies to recruit male participants.

b. Lessons

Utah's Tongan workshop had the highest proportion of male participants, among the interventions whose participants attended voluntarily. The most plausible explanation is that the workshop was held at locations and times in which men were already present. For future genetics education projects, it would be worth considering what specific health-related topics (e.g., prostate cancer), formats, or settings might be particularly appealing to males. The field of teen pregnancy prevention programming, for example, has devoted considerable attention over the past decade and a half to identifying appropriate "male involvement" strategies, in order to ensure that boys and young men can play an active role in addressing this important health issue (Troccoli, 2006). A "male involvement" approach to genetics education might leverage lessons learned from efforts to involve males in other health prevention and promotion efforts.

IX.B. Addressing Common Elements of Local Evaluations

Evaluation planning activities began very early in the project and continued through early 2010. As was discussed in Section V.A, all local evaluations had some common requirements and expectations, including IRB approval, development of logic models, implementation of both process and outcome evaluation activities, and a CBPR approach. The CGEN team experienced some challenges and learned some lessons in relation to these common elements.

IX.B.1. IRB Approval

a. Challenges

Local evaluations were required to have ongoing IRB approval for their designs, methods, and instruments. DWDC and CBWCHC, which do not have their own IRBs, used the UIC IRB, which also served as the IRB of record for the national evaluation effort. During a period of turnover among the national evaluation staff, miscommunication arose among DWDC, CBWCHC, and the national evaluation team as to IRB requirements. While this issue was resolved successfully several months later, it did result in delays for DWDC's CHW training

implementation and CBWCHC's evaluation activities. It also raised some questions about the level of control that community organizations have in multilevel partnerships.

b. Lessons

IRB requirements and timelines should be stated clearly, in writing, at the outset of the project and should be reviewed in an in-person session to ensure that all parties are aware of relevant terminology, forms, procedures, and requirements. IRB matters should be revisited periodically, and particularly after a project experiences staff turnover, to be sure that requirements are being met and that questions or concerns are addressed promptly.

IX.B.2. Logic Models and Program Theory

a. Challenges

Logic models are useful tools for designing interventions and evaluations and for communicating with key stakeholders about program objectives and measurement. Logic models for the overall CGEN Phase I-II efforts and for the local site Phase I-II efforts were developed in late 2007 and early 2008. Local sites were particularly encouraged to develop models that reflected common behavioral and social theories underlying effective health promotion interventions; according to these theories, factors such as attitudes, self-efficacy, and intentions influence behaviors, which in turn impact health outcomes (NCI, 2005). While the logic modeling activities did appear to help move *evaluation planning* forward, they were in effect retroactive with respect to *program planning*. That is, local site interventions had already been developed, so models were created to fit the existing plans, limiting the opportunity to use logic modeling to strengthen intervention approaches.

b. Lessons

Training in logic modeling and formal theories at the outset of the project would likely have helped sites to plan programs that further leveraged existing knowledge of “what works” to change the determinants of the targeted health-related behaviors and the behaviors themselves. Such training could have fruitfully included local site staff, local evaluators, CAB members, and (as appropriate) other local community constituents, so that each local team could have worked together to apply the concepts to their CGEN Phase I-III efforts.

IX.B.3. Common Process and Outcome Indicators and Measures

a. Challenges

As was discussed above, early in the project, there were plans to establish some common cross-site output and outcome indicators and an associated set of common core intervention participant survey items. In addition, there were plans to develop a cultural competence assessment tool that would be administered to each local site. However, these plans were abandoned in late 2007, due to a combination of factors. The local sites’ divergent populations, interventions, and timelines presented challenges to developing common measures, and disagreement among the sites

concerning the validity of specific cultural competence measures prevented consensus on a final version of the draft cultural competence tool. In addition, turnover among the national evaluation team in 2007 left a gap in expertise and leadership at a crucial time in the project timeline. As a result of these factors, each site ultimately developed and deployed its own separate evaluation tools, and as Phase II drew to a close, the national evaluation team found it challenging to “roll up” or summarize CGEN program characteristics, reach, and effectiveness.

b. Lessons

In hindsight, it would have been useful for the team to have made a greater effort—back when all sites were still in Phase I—to agree upon and build in at least a few common cross-site measures and specific survey questions. These might have addressed selected site characteristics, participant demographic features (e.g., age, gender), and knowledge and attitudinal items, such as whom people get their genes from. Addressing and collecting data on common indicators would have allowed the team to better assess the reach and impact of CGEN as a whole. The Prevention Research Center of Michigan has developed a cross-site evaluation tool that has been utilized with community health projects that differ in health focus, methodology, geographic coverage, and target populations (Kruger et al., 2010). It covers incorporation of evidence-based practice, process and outcome indicators, cultural competence, and sustainability. This tool could serve as a model or starting point for the development of cross-site evaluation instruments for other projects.

IX.B.4. CBPR Approach

a. Challenges

It was expected that community involvement would be robust throughout all project phases. In particular, Phase II implementation and evaluation activities could involve community constituents in a number of ways, including (but not necessarily be limited to) the following:

- Involvement of other local community organizations as program implementation sites and participant recruitment partners.
- Participation of community members in intervention delivery and documentation (e.g., as teachers or facilitators).
- Participation of CABs or other community constituents in evaluation design development, instrument development and translation, interpretation of findings, and/or dissemination of findings.

Sites’ intervention approaches, resources, and readiness for participatory approaches varied, and as a result, the nature of community involvement in Phase II also varied. All of the sites leveraged their connections with local community organizations to obtain program implementation venues, recruit participants, and/or deploy their materials. CBWCHC disseminated brochures through its organizational networks. DWDC and Howard collaborated with community-based organizations that provided workshop venues and recruited workshop participants. Utah did as well, through its partner, the National Tongan American Society. Utah also used its connections with local school districts to recruit teachers to pilot-test the school-based interventions in their classes. For several of the community workshop interventions, Phase

II timelines were delayed by challenges in working with community partners to set up and recruit participants. Community partners had no shortage of good will, but had competing priorities for their time and/or space.

DWDC and Utah involved community members in intervention delivery and/or documentation. Specifically, one of DWDC's CAB members, a genetic counselor who worked in the local community, helped to train CHWs—who were all local community members—to deliver the community workshops. In Utah, local school teachers and a Tongan community leader (who was also a CAB member) delivered the interventions and collected participant data. While in many cases these processes ran smoothly, in other instances challenges arose. As in the case of the community partner organizations, there was no shortage of good will among community leaders and members; however, competing responsibilities (jobs, family, personal issues) and different backgrounds and skills led to some timeline delays, misunderstandings, and setbacks. For example, DWDC's expectation that CHWs would (with training) be able to handle both workshop facilitation and evaluation data collection responsibilities turned out to be too ambitious. Numerous problems with data collection were noted during the first community workshop pilot, resulting in serious data validity concerns; ultimately a third party was brought on board to handle workshop evaluation tasks so that the CHWs could focus on workshop facilitation.

Participatory evaluation approaches were, on the whole, not as robust as expected. In particular, CAB and other community involvement in evaluation design, instrument development, and interpretation and dissemination of findings was somewhat limited. As was discussed above, CBWCHC reported to their CAB periodically on Phase II progress and obtained their feedback. Howard met with their CAB at the end of each pilot study to share and discuss findings and implications. Utah involved the Tongan/Pacific Islander CAB in review of the Tongan translations of the evaluation instruments, which proved to be very beneficial. In addition, Utah shared their pilot study findings with the respective Hispanic/Latino and Tongan/Pacific Islander CABs. They also shared the school-based findings with the respective school districts and principals, but received no feedback from these parties. DWDC's CAB did not convene during the reporting period (2007-2010), but the local genetic counselor on the CAB and the CHWs were consulted on several questions concerning the evaluation instruments, and some of the community workshop findings were shared and discussed with the CHWs. DWDC also delivered a local press conference on their evaluation findings that attracted one CHW and many community members. Members of the CAB were invited, but did not attend. A couple of sites experienced challenges keeping CABs or other community constituents engaged over long periods of time, as intervention materials were revised and planning processes were carried out. In particular, loss of interest and competing professional and personal responsibilities resulted in attrition.

b. Lessons

As Cashman et al. (2008) and others have noted, involving community constituents robustly and effectively takes considerable planning and often involves lengthy timelines. Setting specific goals for community involvement, delineating all parties' tasks and timelines clearly (in writing) up front, providing incentives (such as stipends), having periodic check-ins, providing needed

training or support, and celebrating successes (large and small) can all help to keep community stakeholders engaged and involved, even when there are strong, competing pulls on individuals' and organizations' time and other resources.

IX.C. Developing and Deploying Appropriate Instruments and Procedures

All of the sites experienced some challenges developing and implementing appropriate instruments and evaluation procedures for their target populations. An overarching lesson concerns the importance of setting aside time and other resources to conduct small-scale pilot-testing of instruments and procedures before deploying them in a larger-scale field test.

IX.C.1. Addressing Linguistic, Literacy-Level, and Cultural Considerations

a. Challenges

Developing survey instruments that would be accessible to low-literacy populations was challenging, particularly since the topic of genetics necessarily includes a great deal of technical (i.e., scientific and medical) terminology. Translating English survey instruments into different languages, while maintaining equivalence of meaning with the English versions, also presented some difficulties. In some cases, problems with instruments were identified after the instruments were already in use in the field, and pilot studies had to be stopped so that instruments could be reviewed and edited.

Additionally, some sites found that they needed more time than originally anticipated for program staff (educators, facilitators, or assistants) to read survey questions and answers aloud to the group, and/or to work individually with participants so that they could understand and respond to the instruments. In such cases, evaluation activities competed with intervention activities for the limited time with participants, and the result was a truncated intervention and/or high rates of missing data.

In addition to individual-level literacy issues, some cultural groups have a particular tradition of providing feedback or commentary in oral (as opposed to written) format. As one site found, for such groups, completing written surveys can be a particularly challenging task.

Given these factors, local evaluators struggled with the length of their surveys and with how to obtain high quality quantitative and qualitative data. On the one hand, they did not want to overwhelm participants or absorb too large a proportion of the contact time with them, as this would impede effective intervention delivery. On the other hand, they needed to collect data of sufficient range, depth, and quality to evaluate the interventions adequately.

b. Lessons

The March of Dimes' training for the CGEN team in development of low literacy materials (November 2007) provided useful information to local evaluators and project coordinators that aided with instrument development. In addition, involvement (by some sites) of CABs or other community constituents to prepare translations and/or review draft instruments also helped to

improve instrument comprehensibility and appropriateness. Many of the local evaluation studies would have benefited from additional involvement of community stakeholders in these processes, however. Building in time for group translation and/or review, as well as instrument pilot-testing with at least one focus group representing the target population, would likely have improved the quality of some instruments and the validity of the data collected (Marín & Marín, 1991, Pennell et al., 2010).

Additionally, as was noted above, instruments must be kept as succinct as possible to avoid overwhelming research participants. This requires evaluation teams to make difficult decisions about what is truly most important to measure—a process for which logic modeling can be particularly helpful.

It is also often necessary to plan for extended survey administration times so that accommodations can be made for low-literacy group members. As Howard found, reading questions and answers aloud while showing and pointing to them (on a screen, whiteboard, or flipchart) can help study participants to understand and respond (see also Conner, 2004). Having additional assistants or other support staff available to answer questions one-on-one can also help to ensure that participants can provide truly informed consent and participate fully in the evaluation.

Finally, although some sites used focus groups to assess the utility and cultural and linguistic appropriateness of individual CGEN materials (i.e., brochures, booklets), none conducted post-workshop or post-curriculum focus groups or in-depth interviews with intervention participants. In some instances, such methods might have provided additional insight into important topics such as the cultural and linguistic appropriateness of the full interventions as delivered in “real world” contexts, key learnings and behavioral intentions that participants were leaving the intervention with, the barriers to behavioral change that remained, and how the CGEN interventions might better address those barriers.

IX.C.2. Managing Evaluation Logistics and Ensuring High-Quality Data

a. Challenges

All of the local CGEN evaluation studies had multiple logistical issues to address, such as how best to explain evaluation instruments and procedures to participants, how to link pre- and post-test surveys, how to document various aspects of program implementation, and how to minimize missing data. Some sites experienced more challenges than others in relation to these issues.

b. Lessons

Through periodic conference calls and more informal calls and email, sites were able to discuss and share a number of evaluation logistics best practices. These included (but were not limited to) the following:

- Ensure that participant surveys are linguistically, culturally, and literacy-level appropriate and not overly burdensome.

- Order survey questions so that less sensitive questions are asked before more sensitive questions.
- Color-code pre- and post-test surveys to facilitate instruction-giving and survey completion.
- Use anonymous project code numbers and pre-prepared packets to ensure that pre- and post-test surveys can be matched.
- Collect evaluation instruments as they are completed by participants, instead of waiting until the end of a program session to collect all instruments at once.
- When appropriate, use trained graduate students or other third parties to answer group intervention participants' technical questions and/or to handle (or assist with) evaluation procedures, so that facilitators or educators can focus on delivering core content and facilitating group discussion.
- Incentivize evaluation participation using culturally and geographically appropriate incentives.
- Ask facilitators or a third-party observer to complete a detailed checklist on what intervention activities are implemented and how participants responded to them.

IX.C.3. Maintaining and Documenting Fidelity to Core Intervention Components

a. Challenges

Limited contact time with participants, and competing program vs. research needs, often made it difficult for program staff to deliver the planned intervention activities fully and consistently. In addition, for some interventions, differences among participants and among program staff with respect to backgrounds, skills, and interests led to variations in intervention content and delivery.

Because such variations present challenges for assessing program outcomes, documenting program delivery is an important evaluation component. Yes, some interventions did not formally document program delivery; for others, documentation was extremely limited.

b. Lessons

Instruments for documenting adherence to and deviation from core program activities should be developed collaboratively by local evaluators and program staff, to help ensure that key information can be collected without overburdening program educators or facilitators. When program educators or facilitators will be documenting program delivery themselves, training should be provided so that it is clear what information should be captured, where, when, and how. When possible, having an external observer document program implementation can be very useful, as it can bring greater objectivity to the assessment and also alleviate additional evaluation burden on program staff, who are already occupied with intervention tasks.

IX.C.4. Monitoring and Responding to Evaluation Findings

a. Challenges

In research studies involving minimal risk to human subjects, it is common to collect all of the data before conducting analyses. While this practice helps to ensure that analyses are based on a robust sample size, it often precludes awareness of crucial intervention or evaluation problems until the end of the study—when it is too late to fix them. As was indicated above, several sites experienced important implementation and/or evaluation challenges. In the case of CBWCHC’s second pre-counseling workshop pilot, however, ongoing monitoring of outcome data made staff aware of the issues early on—just a month or so into data collection, when the sample size was still relatively small. The local team was able to promptly stop the study, revise the relevant implementation and evaluation procedures, and initiate a third pilot. In the case of some other sites, larger datasets were collected, over longer time periods, before the data were analyzed and the decision was made to revise procedures and initiate a new pilot.

b. Lessons

Although it can be time-consuming (and can carry a risk of drawing invalid conclusions based on small datasets), ongoing monitoring of evaluation data can provide crucial input to team decision-making. In particular, investing in monitoring activities up front can save time and money later, as teams can make informed decisions to stop, adjust, and re-start studies, if warranted, before full budgets and timelines have been expended.

IX.D. Achieving Change Among Participants

IX.D.1. Challenges

As was discussed above, while knowledge of numerous genetics and health topics increased overall from pre- to post-test across sites, responses to knowledge questions seldom reached 100% (or nearly 100%) correct for any survey item, for any population. A notable percentage of participants still appeared to be leaving workshops with misconceptions or misunderstandings. This was likely due to a combination of the abstract nature of much of the material, diverse participant learning styles, and varying culturally-associated beliefs about heredity and health. (It is also possible, in some cases, that limited literacy resulted in validity issues with the data. That is, although all of the sites took steps to address limited participant literacy skills—e.g., by reading questions aloud or helping participants one-on-one—it is still possible that some participants had correct knowledge but were unable to demonstrate this knowledge through the written surveys.)

IX.D.2. Lessons

To help address the knowledge gaps that appeared to remain even after intervention participation, two sites began providing the correct answers to the evaluation survey knowledge questions immediately following post-program data collection. One provided a written list of correct answers to participants as they left the workshop venue; the other reviewed the items

orally prior to the end of the workshop and also provided a take-home sheet. This helped to ensure that participants left with accurate information. Workshop facilitators also provided participants with contact information for resources that could address any further questions. More broadly, all sites found that helping participants to personalize the information—e.g., by providing culturally and geographically relevant examples, encouraging documentation of family health histories, and stressing relevance of the material for one’s children and grandchildren—was a useful strategy for generating interest in genetics and intentions to engage in positive behaviors related to genetics and health.

IX.E. Adhering to Timelines

IX.E.1. Challenges

Phase II was originally projected to last one year—specifically, all sites were expected to initiate and complete their Phase II activities within the period June 2006-May 2007. However, in practice, local sites’ Phase I activities were delayed, resulting in a late start to Phase II. Once initiated, Phase II in effect lasted for over 3.5 years (i.e., through early 2010). The Phase II delays were the result of the factors discussed above, as well as others, including project staff turnover at various sites and several sites’ need for more time than expected to make multiple rounds of edits to intervention materials, in response to feedback from community constituents.

Delays to local site Phase II activities and deliverables delayed national evaluation activities and deliverables. More crucially, the lengthy Phase II significantly reduced the time and budget available to the CGEN team for Phase III dissemination activities.

IX.E.2. Lessons

As Cashman et al. (2008) and others have noted, CBPR projects need lengthier timelines than many other types of research projects. While the original CGEN timeline was overly ambitious, it is hoped that among all CGEN partners and in the field more broadly, application of the lessons highlighted above and below may help to inform more realistic timelines and streamline processes for future projects.

IX.F. Engaging in Multisite/Multilevel Projects

One of the benefits of multisite/multilevel projects is that they bring together parties with complementary experience and expertise that can be leveraged to generate ideas and solve problems. The challenges of multisite and multilevel projects, however, include the difficulty of establishing common indicators and “summing up” reach and effects, an issue that was discussed above (see Section IX.B.3). Other challenges (discussed below) include miscommunications and tensions concerning roles and responsibilities, and how best to capture outcomes (expected or unexpected) among the partner organizations and staff.

IX.F.1. Roles and Responsibilities

a. Challenges

In a multisite/multilevel project that involves numerous partners, communication challenges and tensions over roles, responsibilities, and timelines inevitably arise, at least occasionally. In mid-2006, March of Dimes drafted a Memorandum of Collaboration whose purpose was to “outline the guiding principles of collaboration that define the Consumer [Community] Genetics Education Network (CGEN) Project as ‘participatory’,”¹³ so that collaboration could be maximized and tensions and misunderstandings avoided or minimized—and resolved quickly if or when they arose. The memorandum outlined project goals and objectives, principles of collaboration, roles of the various partners, and communication and dissemination strategies. It was updated periodically; for example, brief IRB guidelines were added in 2008. The memorandum was eventually made part of the annual contracts between March of Dimes and the various project partners.

However, despite the existence of the Memorandum, and good will among all parties to implement its principles, CGEN project partners experienced periodic challenges to the collaborative process during Phase II. For example, as was discussed above, miscommunication surrounding IRB requirements and procedures occurred in 2007-2008 and led to some local site implementation and evaluation delays. In addition, the relative autonomy of the local evaluators vis-à-vis the national evaluators and the March of Dimes was not always clear, and at times was difficult for all parties to balance and negotiate. Finally, as was indicated above, delays in local site Phase II processes delayed national evaluation processes and necessitated considerable adjustment of project-wide timelines and budgets. Staff turnover at the local and national levels contributed to miscommunications, delays, and tensions.

b. Lessons

It is essential to develop and discuss guidelines at the outset of the project and to revisit them periodically (and revise them, as needed) during the project. Maintaining open lines of communication is also critical. Periodic phone meetings among the entire project team and among subgroups afford crucial opportunities for updates, discussion, and clarification.

In addition, procedures and materials should be in place to debrief outgoing staff members and orient new team members, to reduce challenges that can arise in context of staff turnover. It is particularly crucial that formal project orientations take place at the local and national project levels, and that they include discussion of goals, principles, project organizational structures, communication protocols, and the location of online materials and files.

¹³ “The Consumer Genetics Education Network (CGEN) Memorandum of Collaboration June 2006”, p. 2. See file entitled “CGEN Collaborative Agmt 6-19-06-draft”, last updated August 10, 2007. Accessed via March of Dimes Dimension Workspace on July 2, 2010.

IX.F.2. Capturing Partner-Level Outcomes

a. Challenges

Multisite/multilevel projects frequently have effects—expected or unexpected—on not only the community members who are served or reached by the project interventions, but also the partner organizations, staff, and community collaborators who plan, implement, and evaluate these interventions. Yet, often little attention is given to tracking and documenting outcomes among project partners. The final version of the overall CGEN logic model (Figure 1 in Section I) included only limited reference to such outcomes; for example, one desired outcome was articulated as: “Increased/improved skills, self-efficacy, attitudes, and intentions...to plan, implement, manage, evaluate, and/or sustain genetics education projects and programs (among teachers, CHWs/promotores, project/site staff, & local advisory boards).” Additional outcomes among organizations and staff were sometimes mentioned in quarterly reports, were discussed from time to time in project meetings, and were noted briefly above in Section VIII. However, there was no formal attempt in Phase II to document systematic, comprehensive information across sites. As a result, the richness and range of CGEN outcomes has not been fully captured.

b. Lessons

A brief annual cross-site questionnaire might have helped sites to document organizational, staff, and partner outcomes more systematically, although it would have added additional reporting burden to the sites, which already had numerous competing responsibilities. Interviews would have been another option; however, a key lesson from Phase I interviews with key stakeholders was that the time required to analyze the many hours’ worth of interview transcripts placed considerable burden on the national evaluation team, which (like the sites) also had many other responsibilities. In short, achieving an appropriate balance between competing research and programmatic needs is a common challenge in CBPR work that has no “one size fits all” solution.

X. Implications for Practice, Research, and Policy

The experiences and findings of Phase II of the CGEN project have a number of important implications for practice, research, and policy. Key implications are summarized briefly below.

1. In real-world projects, there will always be tensions between programmatic and research needs. Balancing these needs effectively requires open communication, close collaboration, and trust among program and research staff, as well as creativity and compromise.
2. Similarly, multisite/multilevel efforts need effective communication and meaningful collaboration to be successful. Laying out clear goals, agreeing on guiding principles, signing formal agreements, and having regular check-ins can help to avoid misunderstandings and promote strong working relationships. Up-front and ongoing capacity-building on key approaches and procedures is also important, particularly in the context of high project staff turnover. A coordination and technical assistance center that is dedicated to implementing these activities can serve as both the "glue" that keeps partners together and the "oil" that keeps the project moving smoothly forward. However, in CBPR projects, it is also essential that all partners feel empowered and remain actively involved in decision-making. Balancing the imperatives of moving forward—but not leaving anyone out or leaving anyone behind—is one of the biggest challenges of CBPR work.
3. CBPR projects take “bottom up” approaches, in which needs, assets, goals, and strategies emerge from and are developed by the community; however, research tools and frameworks (such logic modeling and formal behavioral and learning theories) can still be fruitfully applied. Up-front capacity-building around both research- and community-driven tools and frameworks is essential so that all stakeholders have a common language and shared understanding of processes.
4. It is also essential to involve community constituents actively throughout all phase of a CBPR project, from development and planning to implementation and evaluation to dissemination and sustainability. This involvement may take different forms, but most require that considerable time be built in for the iterative processes involved. Defining roles and tasks, setting realistic timelines, celebrating milestone successes, and providing appropriate incentives can help to sustain community interest and participation, even when timelines are lengthy.
5. For their part, community constituents must maintain flexibility and willingness to adapt their plans (e.g., narrowing goals, bringing on additional experts to provide input on technical issues), if it becomes clear that their original aims were not realistic or that their processes have not yielded the intended progress.
6. Even when goals, approaches, and populations differ across interventions in a multisite project, it may still be feasible and desirable to develop a small set of common indicators, measures, and instruments for both individual site interventions and partner-level outcomes, so that it is possible to document and sum up overall project impact.
7. Obtaining community input to evaluation instruments and protocols and then conducting a small-scale pilot requires time and resources but can increase the likelihood that a subsequent

larger-scale evaluation will run smoothly. Monitoring evaluation activities and findings in real time can help to ensure that unanticipated problems are identified and addressed as rapidly as possible.

8. Beliefs about heredity and health are often linked to deeply held cultural beliefs. Moreover, genetic science is a discipline that many people consider to be far removed from their everyday life concerns. These factors can make it challenging to increase even basic knowledge of certain genetics concepts. Yet, it is possible to educate people about genetics—and the interrelationships among genetics, the environment, behavior, and health—in ways that make the material relevant and accessible. Across cultural and linguistic groups, collection of family health history has emerged as a key strategy for generating interest in genetics and health, and helping community members to personalize and act on key messages concerning how they can reduce their risk (and their family members' risk) of developing genetically-linked diseases (Kaphingst et al., 2009; Petruccio et al., 2008; Vogel et al., 2007). Genetics education interventions and materials should include images and examples that are culturally, linguistically, geographically, and literacy-level appropriate and highly salient to the target audience, to emphasize the relevance of the material to their lives.
9. Reaching men with genetics education programming may require targeted strategies, such as leveraging existing settings or activities frequented by men and addressing topics of particular interest and relevance to men. Best practices for involving males in other health issues (e.g., teen pregnancy prevention, family planning) might be fruitfully leveraged in genetics education programming.
10. One of the goals of CGEN was to increase consultation with health care providers about genetics and health. Phase II data suggest that some CGEN interventions increased intentions among participants to engage in this behavior. However, as an audience member at the 2009 APHA Annual Meeting CGEN presentation session asked, do health care providers (such as primary care physicians, nurse practitioners, and obstetricians) have the information and skills to respond appropriately to community members' overtures? Educational programming and related resources for practicing clinicians and for clinicians-in-training need to build their knowledge of genetics and health, as well as their skills to interact appropriately about these topics with persons of diverse cultural and linguistic backgrounds and literacy levels (Harvey et al., 2007; Saleh et al., 2009; Telner et al., 2008). Increasing genetic literacy and cultural competence among health care providers is an essential complement to ongoing community-focused genetics education efforts.

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