Empowering Underserved Communities to Reduce Health Risks Through the Development of Community-Based Genetics Education Programs

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Community Genetics Education Network Overview

- Cooperative agreement between March of Dimes and Health Resources and Services Administration (HRSA)
- Four community partners developed and implemented population-specific genetics education programs
  - Different interventions based on needs assessments and preferred learning methods
- Identified the most effective ways to increase genetic literacy among diverse minority populations and determine best practices
- Used principles of community-based participatory research
- Evaluated planning process, implementation, and outcomes

Summary of Evaluation Sample Sizes & Outcome 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 (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. with genetic counselor, I vs. C)
DWDC	Community workshops: Pilot 1	114 adults	++[1]	N/A	N/A	++	N/A	N/A
	Community workshops: Pilot 2	133 adults	++	N/A	N/A	++	N/A	N/A
Howard	Community workshops	183 adults	++[2] (pre to post)	N/A	N/A	+ (post only)	+ (pledge fulfillment; post only)	N/A
Utah	Fifth grade curriculum/material	6 teachers; 159 students	++ (pre to post)	++ (confidence in knowledge) + (interest to learn more; post only)	N/A	N/A	N/A	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[3])	N/A	N/A
	Community workshops	95 adults	++ (pre to post)	NS (belief[4]) + (interest to learn more; post only)	N/A	+ (post only)	N/A	N/A

Key: ++ = statistically significant positive finding(s); + = "clinically positive" finding, no test of statistical significance; NS = not statistically significant; I = intervention group; C = comparison group; N/A = Not applicable because not measured

Notes: [1] Significant positive findings were found for genetics and health knowledge; healthy pregnancy knowledge findings have been set aside because of methodological problems. [2] Change in overall knowledge score for family health history was not significant. Change in overall knowledge score for race, genetics, and health was significant [3] 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. [4] 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.

Project Findings

- The 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.
- There was relatively low baseline knowledge of some basic concepts, such as understanding that half of their DNA comes from their mother and half from their father. However, there was notable improvement from pre- to post-test. See table.
- A focus on the importance of lifestyle and knowing one's family health history for mitigating the expression of genetically linked diseases prevalent in the respective communities helped to engage participants and make the material relevant and engaging.
- Interventions that measured intention to talk with family regarding family health history found a significant increase in intention.
- Among the interventions that targeted both males and females and had voluntary participation (vs. required school classroom participation), the percentage of males was relatively low, ranging from 10% for the CHW trainings to 42% for community workshops for the Tongan population.
- Overall satisfaction with each intervention was high, including satisfaction with knowledge of the presenter, length of workshops, information provided, quality of materials and handouts, and information learned.
- Local and national CGEN team members reported gaining greater experience with CBPR; improved ability to address issues of cultural and linguistic competence; expanded or strengthened relationships with (other) community agencies; and learned how to better evaluate and disseminate project materials and findings.

Site, Intervention, and Knowledge Question[1]	N and Missing n	Correct Responses			
		Pre		Post	
		n	%	n	%
DWDC Community Workshop 1 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
DWDC Community Workshop 2 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
Howard Community Workshop You get all of your genes from our mother and none from our father. (Yes/**No**)	N=183, Missing=34	138	93	138	93
Utah Fifth Grade 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
Utah Tongan Community Workshop 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

[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.

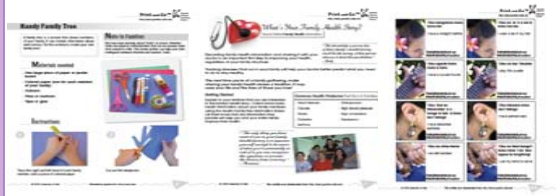
Educational Interventions

Dominican Women's Development Center
www.dwdc.org

- Bilingual English/Spanish genetics training curriculum for Community Health Workers (CHWs).
- Genetics education workshops for the community, including a local resource guide for the Washington Heights/Inwood community.

Genetic Science Learning Center at the University of Utah
learn.genetics.utah.edu & teach.genetics.utah.edu

- Collaborated with the Utah Department of Health.
- Bilingual English/Spanish school materials for fifth grade and secondary school biology or health classes that meet U.S. National Science Education Standards.
- Materials for general audiences adapted from school curricula.
- Tongan/Pacific Islander community workshop materials in partnership with National Tongan American Society.



Charles B. Wang Community Health Center, Inc.
www.cbwchc.org

- Genetics education workshops with a bilingual health educator for at-risk prenatal patients prior to meeting with a genetic counselor.
- Five bilingual Chinese/English brochures and two available in Korean/English.

Department of Community and Family Medicine and National Human Genome Center at Howard University
www.myfamilies.org

- Community education workshops for African Americans, *Family Health History, Genetics and Your Health: Educating the African American Family*, that expand on information provided in two booklets:
  - *Race, Genetics, and Health*
  - *Planning for a Healthy Future*
- Video on family health history used in community education workshops.

Lessons Learned & Implications

- You don't have to be in or of the community to be successful in engaging the community if you actively involve community constituents and stakeholders throughout the process.
- Fostering positive relationships with key on-the-ground partners is essential to reaching the intended community members, particularly when the lead agency is not itself a community-based organization.
- Multiple levels of participation are beneficial in bringing together academics, clinicians, and CBOs. However, with multi-site/multi-level projects clear goals, guiding principles, and formal agreements need to be established early in the process.
- 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.
- Across cultural and linguistic groups, 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 of developing genetically-linked diseases.
- Reaching men with genetics education programming may require targeted strategies, such as leveraging existing gatherings in which men participate and addressing specific topics of particular interest and relevance to men. Best practices for involving males in other health issues might be fruitfully leveraged in genetics education.

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