

# **Latino Consumer Genetics Education Network: Meeting the need for a culturally and linguistically appropriate genetics education program for Latinos in NYC**

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# Dominican Women's Development Center



## MISSION STATEMENT

- To organize women to actively participate in the elimination of gender inequality, all kinds of violence and to promote social justice;
- To provide multicultural, holistic, social services as well as educational, economic, and cultural development programs.

## SERVICES

- Health & Wellness Program
  - Domestic Violence Program
  - Educational Program
- General Preventive Program
- Youth Development Center
- Gender Unit
- Community Organizing Project



# Latino Consumer Genetics Education Network

## Goals

The goals of this program are to build community capacity and to increase genetic awareness in the Latino community based on completed needs assessment conducted in the Washington Heights/Inwood area.



# Latino Consumer Genetics Education Network

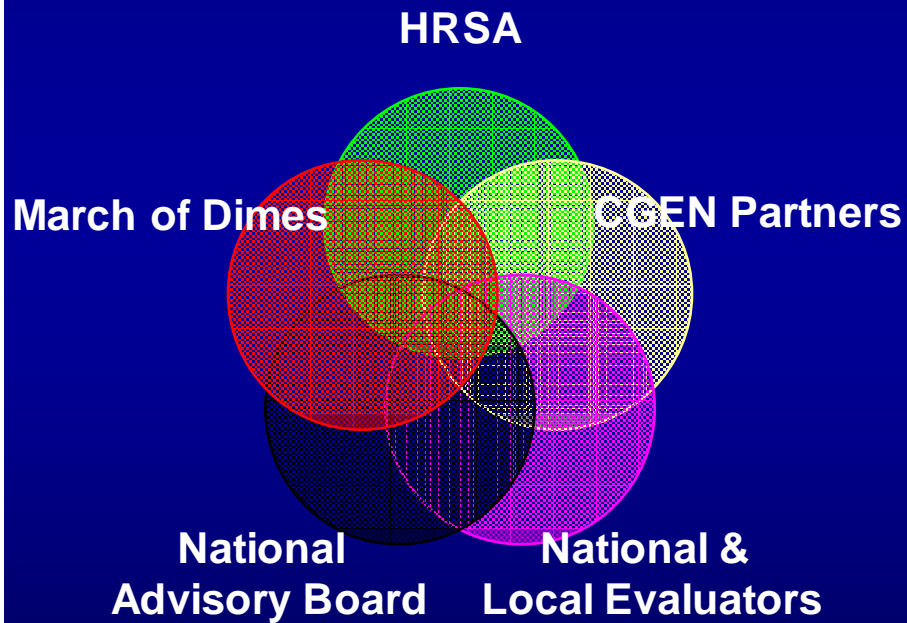
## Objectives

- To develop, implement and evaluate a genetics training curriculum aimed at Community Health Workers (CHWs)
- To develop and evaluate genetics educational materials that would complement the genetics training curriculum for CHWs
- To increase community awareness and education about genetics through the dissemination of genetics and health related information and resources.
- To conduct community genetics education activities facilitated by trained CHWs.

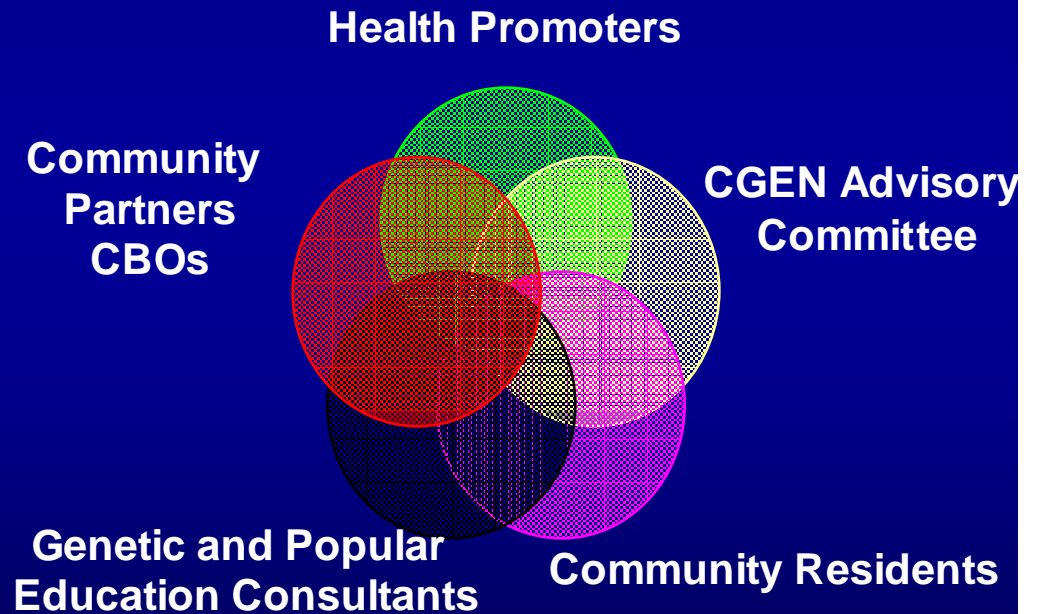


# Collaborative & Community Participatory Approach

## National Level



## Local Level



# Demographics



- According to 2000 census, the Washington Heights/Inwood community has about 320,138 residents.

- About 74.1% are Latinos (54.1% are Dominicans).

- Many of the Dominican/Latina/o residents of WH/I were born outside of the United States.

- Approximately 21% of its residents were below the poverty level.

- Unemployment rate is higher than the NYC.

- Almost 70% of the population report no college education and 25% reporting less than 9 years.

# Project Background

## NEEDS ASSESSMENT

As a result of our comprehensive genetic literacy needs assessment in WH/I (2002-2004) we were able to document:

- Community's knowledge and attitudes regarding genetics
- Consumer preferences in terms of areas and sources of health information
- Access to health & genetics services in the community
- Information to assist in the implementation and evaluation of Latino CGEN Project activities



## GENERAL RECOMMENDATIONS

To develop and disseminate culturally and linguistically appropriate health information on:

- Advances in genetic research
- Interaction between genetics and the environment and its effect on health
- Genetics public policy issues
- Genetics ethical, legal and social implications (ELSI)
- Community and health care system's capacity to provide genetic services

# Why Community Health Workers (CHWs)?



- Studies show that CHWs have been successful in disseminating culturally and linguistically appropriate health education to minority and underserved populations in the US and Latino America.
- CHWs are people from the community who have the language and cultural understanding of the target population.





# Project Design

- Guided by the principles of community-based participatory action research
  - Active community participation
  - Participatory evaluation methodology
- Utilized a Community-based Participatory Partnership involving different sectors such as: CHWs, community residents, CBOs, local advisory board, evaluator and health professional organizations.
- Regular network meetings and community activities are held as part of the development and implementation process of the genetics educational materials and to facilitate community discussions with health professionals and access to health services.



# Development of a Community-Based Bilingual Training Curriculum



1. Participatory plan of action was created.
2. Recruitment of CHWs and bilingual expert in genetics.
3. Community meeting with the genetics expert.
4. Genetics expert suggested 10 topics and CHWs added two more.
5. Ten topics were developed in Spanish and reviewed by CHWs, community residents and health professionals.
6. Several experts were hired to assist in the development process.
  - CHW Curriculum Development expert
  - Scientific Reviewers
  - Low Literacy Consultant
  - Professional Translators



# Development of a Community-Based Bilingual Training Curriculum

6. 12 modules on genetics education were created and reviewed by CHWs, community members, CGEN Advisory committee, HRSA, MOD and CGEN partners
7. The 12 modules were compressed into 6 modules to make them more community oriented. A slide presentation was created for training facilitators for each module.
8. Two community education workshops and flipcharts were created based on the training curriculum to be used by the trained CHWs.
  - I. Latino Genetics: Healthier and Wiser Living
  - II. Latino Genetics: Take Action and Know Your Rights



# CHWs Contributions

- ❖ Assisted in the development of a highly participatory approach to health education
- ❖ Recruited and engaged community members
- ❖ Served as critics, contributors, and partners in the development of educational materials and evaluation
- ❖ Delivered the genetic information in a meaningful way to the community
- ❖ Kept the project focused on the real needs of the community
- ❖ Helped to identify ways to reach out to a variety of people
- ❖ Ensured that terms, images and themes used in the educational materials were relevant to our community



# Best Practices for Latino Community Engagement

- As much as possible, involve community residents, CHWs, Program Coordinator, Funders, and Consultants from the planning stage.
- Involve community members and people who are affected directly or indirectly by a genetic and/or health condition. They are more likely to be attracted and committed to the project than staff members from CBOs.
- Include the Advisory Committee earlier in the development process.
- Hold regular network meetings in a consistent basis to help maintain the interest and enthusiasm of members in the project.



# Cont... Best Practices for Latino Community Engagement

- Provide constant, but customized training to CHWs according to the community needs. Additional training were provided on Breast Cancer, Epilepsy, Sickle Cell & Public Communication skills.
- Rely on local resources/key people first.
- When necessary seek resources/key people out of your community.
- Allow EXTRA time when having a participatory approach to ensure community involvement at all levels and in every step of the project. Consider that each draft may be reviewed several times.
- Provide remuneration, incentives, and constant feedback on their progress.
- Always develop educational materials on the primary language of the community involved and/or targeted.

# Challenges

- Participatory process requires more time than top down approaches.

- Recruitment of a bilingual geneticist.

- Recruitment of local CBOs that will be interest in genetics education.

- Maintaining people's interest and motivation in the project.

- Active involvement of the Advisory Committee.

- Use of local resources on genetics and translation of materials.

- Working with several scientific reviewers and consultants.

- Maintaining low literacy level of scientific information and terms.

# Acknowledgements

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