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Community-based culturally competent approaches in improving access to genetics information for at-risk Asian American women

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The Women's Health Department at the Charles B. Wang Community Health Center, in collaboration with a network of national and community partners which include the March of Dimes and the US Health Resources and Services Administration (HRSA), developed initiatives to increase genetic education and awareness among Asian American pregnant women and women of child bearing age. The primary goal of the project is to improve patient understanding of prenatal screening for early identification of children with metabolic and genetic diseases that are particularly relevant to Asian American communities. The project's current objectives are to: 1) develop educational brochures to increase awareness of risk factors and understanding of genetic disorders; 2) develop and field test a genetics education workshop curriculum; 3) convene focus groups of consumers and health care professionals to evaluate genetic educational materials; 4) initiate a media campaign featuring articles in major Chinese language newspapers addressing issues such as prenatal screening and common birth defects. The Asian American community in New York City faces economic, cultural and linguistic barriers in accessing mainstream health care services. Due to these barriers, pregnant women and women of child bearing age at risk for bearing children with birth defects often lack access to culturally competent genetics education and counseling services. The educational brochures and workshop curriculum are effective and culturally relevant interventions leading to increased patient knowledge and understanding and increased use of genetic services.

Learning Objectives:

Upon completion of this presentation, participants will be able to:

- 1. Understand the need for culturally and linguistically competent genetics education for the Asian American community
- 2. Identify risk factors (e.g., advanced maternal age, family history) for genetic disorders such as thalassemia and Down Syndrome
- 3. Identify innovative approaches that facilitate informed decision making, increase use of genetic services and promote healthy lifestyle changes for high-risk Chinese-American women who are pregnant or of child bearing age and their families
- 4. Describe the collaborative and community-based participatory strategies that improve access to culturally and linguistically appropriate genetics information, resources and services for underserved populations to assist them in making informed decisions about their health