

# Making Community Partnerships Work: A Toolkit



March  
of Dimes®

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**About March of Dimes Foundation**

The mission of the March of Dimes Foundation is to improve the health of babies by preventing birth defects, premature birth and infant mortality. Founded in 1938, the March of Dimes funds programs of research, community services, education and advocacy to save babies. For more information about birth defects, genetics, family health history and newborn screening, visit [marchofdimes.com](http://marchofdimes.com) or [nacersano.org](http://nacersano.org).

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***Ordering Information***

Copies of this Toolkit can be downloaded or ordered from the March of Dimes Web site at: [marchofdimes.com/genetics](http://marchofdimes.com/genetics).



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## ABOUT THIS TOOLKIT

### Background and Purpose

Health researchers have shown that building effective community partnerships helps address the health and social needs of a community. These partnerships allow agencies and community members to join together to identify a common problem and to develop a plan of action to address that problem (Israel, Eng, Schulz & Parker, 2005). The action plan might focus on prevention, education, advocacy or a research program to look at the problem in greater depth.

This toolkit is based on the lessons learned from the national and community partners involved in the Genetics Education Needs Evaluation (GENE) Project. The GENE Project was a 5-year program funded by the Health Resources and Services Administration 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 communities to determine their cultural and language needs in the area of genetics education and develop action plans to address those needs. This toolkit provides the reader with some insight into how these community partnerships were developed.

Creating and sustaining a partnership requires patience, an understanding and appreciation of group process, and **cultural sensitivity**. This toolkit is designed to give you the background and tools you may need to engage a community in a partnership. You will learn how to work with community members to achieve a shared goal.

### Intended Audience

This toolkit is written for newcomers and seasoned organizers, community-based groups, public and private foundations, as well as local, state and federal government agencies. Although it is written for those interested in public health and human services, this toolkit can still be useful to individuals and groups addressing other community issues.

### Terms to Know

There are a number of technical terms used to describe the partnership-building process. We have put the terms in **bold** type and listed their definitions at the end of the toolkit. For example, we use the terms “**community-based participatory partnerships (CBPP)**” and “**community-based participatory research (CBPR)**” in the toolkit. If you are uncertain about the meaning of any term, please check the definitions in Appendix A.

## What's Inside

Here's a brief look at what you will find in the toolkit:

- Benefits of developing working relationships with community groups.
- Ideas on how to work with new groups and communities.
- How to conduct interviews with key community members.
- Challenges and potential solutions to building and sustaining community partnerships.
- Case stories that demonstrate how strategies have been applied.
- Tools to help you create partnerships, such as checklists and sample forms.

## Overview of Sections

We have divided the toolkit into an introduction, the three stages of building a community partnership and appendices. Each stage provides strategies and tools to help you create strong community partnerships. Case stories from the Genetics Education Needs Evaluation (GENE) Project are included to show how these strategies were applied to an actual project.

**Introduction** – describes the principles and benefits of a partnership. A diagram is provided to help you understand the three stages of building a community-based participatory partnership.

**Stage 1** – discusses the need to look at your organization's resources and commitment level before working with a community. A self-assessment tool is provided to help your organization determine its readiness to pursue a community partnership.

**Stage 2** – provides suggestions on how to enter the community and find people who may be potential community partners. This section includes information and tools to help you engage key community leaders.

**Stage 3** – describes how to create a structure that supports and sustains the partnership. Tips on how to work with groups to overcome partnership challenges are also discussed.

**Appendices** – includes a list of definitions, tools, references and additional resources.



# INTRODUCTION

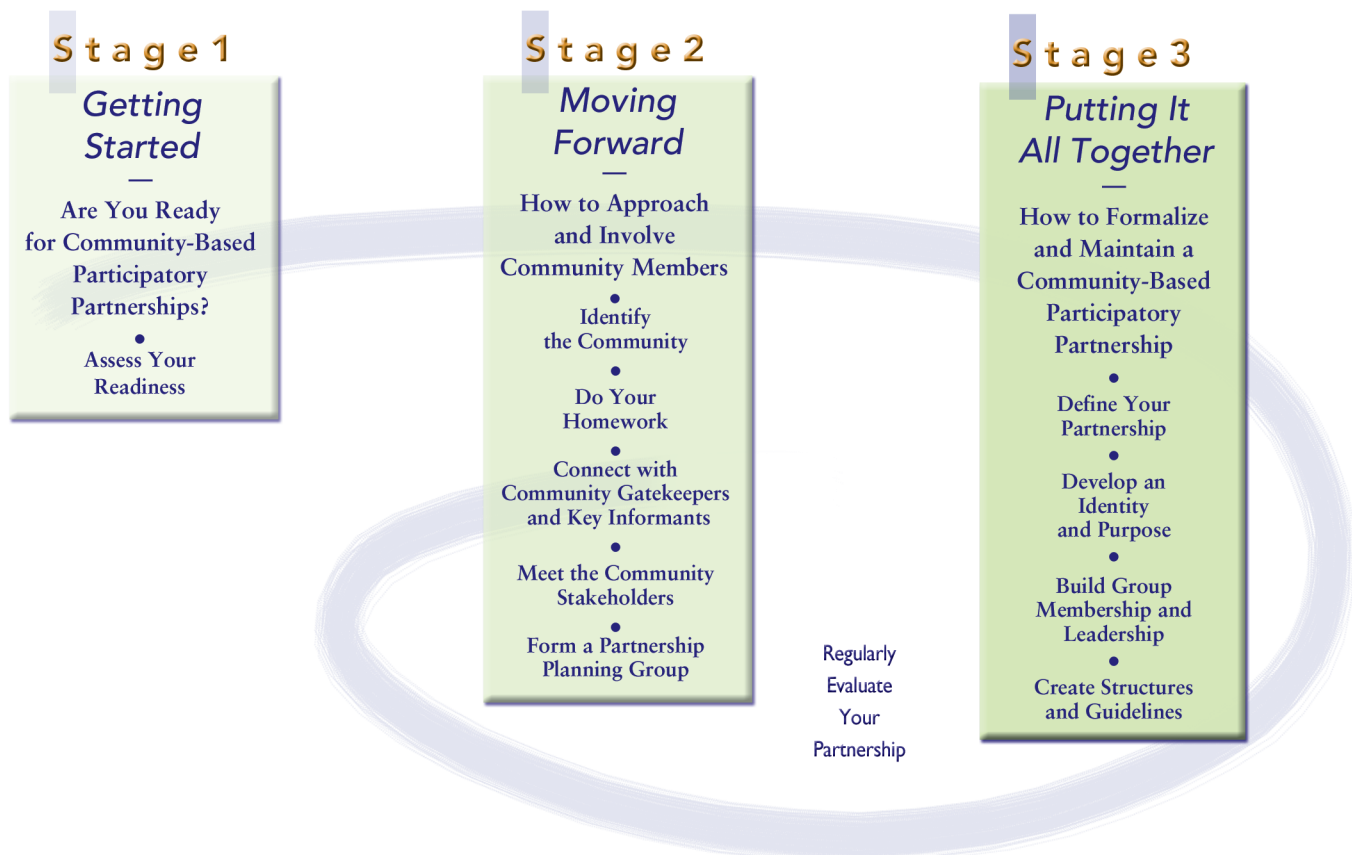
## What is a Community-Based Participatory Partnership?

A **community-based participatory partnership (CBPP)** is a collaborative body of individuals and organizations working together on a common goal or issue of importance to the community. It consists of a mutually beneficial relationship where all parties have shared responsibilities, privileges and power (Connors, 2003). CBPPs are often formed to strengthen the impact of a community education, outreach or advocacy program.

Forming a partnership is also a key step toward working with a community to conduct research. **Community-based participatory research (CBPR)** describes the method of involving community members in the research process. In CBPR, researchers and community members work side by side to identify a problem. Then together, they develop and implement a research plan to learn more about the problem. Results of the research are later presented to the community at large and a plan of action is developed to address the problem (Minkler & Wallerstein, 2003).

The figure below displays the three major stages in developing an effective CBPP. The steps and strategies in each of the stages are described in detail throughout this toolkit.

## Stages of Community-Based Participatory Partnerships



## Key Principles of Community-Based Participatory Partnerships

CBPPs are guided by principles that are listed in the table below. Agreeing on the principles that will guide a partnership is a joint and ongoing effort amongst all group members. These principles are applied throughout the partnership process. In some cases however, additional principles or values may need to be defined to fit the group's vision and purpose, and to reflect the concerns of all group members.

### Key Principles of a Community-Based Participatory Partnership

- Has members who share a common vision, mission, goals and values.
- Has a genuine interest in and commitment to the community.
- Shows mutual trust and respect for partners.
- Recognizes the strengths and contributions of all partners.
- Shares leadership, decision-making power, resources and credit among its members.
- Ensures that each member of the partnership is treated equally.
- Fosters a safe environment for clear and open communication that values feedback from all partners.
- Values the knowledge and expertise of the partners.
- Believes community input is essential.
- Is community driven.
- Values diversity.
- Understands that relationships take time to develop and that they change over time.

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Adapted from Community-Campus Partnerships for Health, *Principles of Partnership* (Connors & Seifer, 2000)



## Benefits of Community-Based Participatory Partnerships

All partners in a CBPP benefit from working together. The table below lists some of the many benefits of a CBPP.

### Key Benefits of a Community-Based Participatory Partnership

- Ensures greater success by involving people most affected by the problem.
- Creates a collaborative environment and a chance to get to know and network with new partners.
- Fosters an environment of mutual learning and understanding of members' strengths, assets and limitations.
- Provides credibility that may come from working with other partners.
- Fosters sharing of resources and creative ideas to develop programs to address community needs.
- Reduces the amount of competing and fragmented services.
- Increases financial and other resources to the whole partnership or certain group members.
- Builds community capacity through training and professional development.

## Summary

A CBPP provides a process and structure for agencies, institutions and communities to work together to address problems important to a community. Although creating a community partnership provides many benefits, it requires time and patience and at times may be challenging. This toolkit suggests that the process of building a CBPP is done in three stages, which are described in the following chapters. It is important to note that the steps described in each of the stages may not happen in order. In some cases, there may be several steps occurring at the same time. At other times, it may be necessary to revisit a stage, especially when the focus of the project changes or new partners join your effort.

## STAGE 1: GETTING STARTED –

### Are You Ready for Community-Based Participatory Partnerships?

#### Stage 1

##### Getting Started

—  
Are You Ready  
for Community-Based  
Participatory  
Partnerships?

•  
Assess Your  
Readiness

Beginning a partnership requires time, skill and resources. Before you begin the process of organizing a partnership, you should consider whether you and your organization have the resources and commitment necessary to make it successful (Flicker, Senturia & Wong, 2000; Hartwig, Calleson & Williams, 2006).

#### Step 1.1: Assess Your Readiness for Community-Based Participatory Partnerships

During this period of self-reflection, think about your own individual and organizational strengths and limitations. Consider the benefits your organization will gain, benefits to the community and any additional concerns. This is also the time to examine the state of past and current relationships with the community. This period of “self-reflection requires active listening, silence, an attitude of discovery, openness and nondefensiveness” (Wallerstein, Duran, Minkler & Foley, 2005).

At this time, an organization and the individuals of that organization may need to assess their level of cultural competency or cultural humility in working with diverse populations. **Cultural competency** is a set of knowledge, skills and attitudes that allows you to work effectively with diverse racial, ethnic, religious, low income and other social groups. While cultural competency may be the ideal end-point, some may view cultural humility as more achievable. **Cultural humility** is a “lifelong commitment to self-evaluation and self-critique” to redress power imbalances and develop and sustain mutually respectful partnerships with communities. Achieving cultural humility involves a willingness to acknowledge forms of inequality, such as institutionalized racism and an openness to learning how to work effectively across cultures and diverse populations (Ibid, p. 41).

Below is a list of questions to consider to help you assess your personal and organizational readiness to form a partnership.

Answering these questions will make you more aware of your and your organization’s strengths and limitations. You will be in a better position to know what you can and cannot offer the community and what gaps need to be filled by your organization and your community partners. As part of this process, you may take note of possible barriers to the relationship-building process. In the next stage, you will be prepared to hear the communities voice their concerns and together you can choose the best path towards partnership that is beneficial to all.



## Partnership Readiness Questionnaire

Answer each of the questions below twice. First from your perspective, then from your organization's perspective.

| — Question —  | Yes | No | Don't Know |
|---|-----|----|------------|
| 1. Are you genuinely interested in and committed to the community?  |     |    |            |
| 2. Why do you want to form a community partnership?<br>(check one or more)  |     |    |            |
| a. Need community partners to meet funding requirements.  |     |    |            |
| b. Need to recruit individuals from underserved populations for a study.  |     |    |            |
| c. Need credibility that may come from partnering with others.  |     |    |            |
| d. Need resources that comes with partnerships.   |     |    |            |
| e. Other:   |     |    |            |
| 3. Does your mission, culture and priorities encourage, support and recognize the value of partnerships?  |     |    |            |
| 4. Do you have a previous history of working with the community?  |     |    |            |
| a. Is this history a positive one?  |     |    |            |
| 5. Do you have any knowledge about the community (for example, culture, norms, politics, socio-demographic characteristics)?                                      |     |    |            |
| 6. Do you have existing relationships with the community?   |     |    |            |
| a. Are these relationships positive?  |     |    |            |
| 7. Do you have the time needed to engage the community and form the partnership?  |     |    |            |
| 8. Do you have the necessary skills to begin and sustain a partnership?<br>(check one or more)  |     |    |            |
| a. <i>Communication.</i> Ability to provide and receive feedback. Strong listening skills. Ability to be a clear and effective verbal and nonverbal communicator. |     |    |            |
| b. <i>Cultural competence or cultural humility.</i>   |     |    |            |
| c. <i>Ability to share power and control over decisions.</i>  |     |    |            |
| d. <i>Group facilitation and interpersonal skills.</i>  |     |    |            |
| 9. Can you contribute any of the following to the partnership?  |     |    |            |
| a. Staff and/or volunteers  |     |    |            |
| b. In-kind resources (e.g. meeting space, technology, dissemination network)  |     |    |            |
| c. Connections to key community leaders and resources   |     |    |            |
| d. Knowledge of the issues/topics to be addressed   |     |    |            |
| e. Training and technical assistance  |     |    |            |
| f. Other: (e.g. financial resources)  |     |    |            |
| 10. What are the potential benefits of a community partnership for your organization and/or project?  |     |    |            |
| 11. What are the benefits of the partnership to the community?  |     |    |            |

## Summary

This section described the importance of assessing your and your organization's resources, skills and commitment to forming a community-based participatory partnership. It provided a tool to help you reflect on your readiness to move forward. If you and your organization have committed to engaging communities further, the next section suggests strategies for identifying and approaching those community partners.

## CASE STORY

### The Genetics Education Needs Evaluation (GENE) Project

In 2000, the March of Dimes received funding from the Health Resources Services Administration (HRSA) – Genetic Services Branch, to develop a consumer network for genetics education. When extensive literature reviews revealed that there was limited research, data and educational materials on genetics for **underserved** communities, the March of Dimes and its existing national partners, Genetic Alliance and Family Voices, saw an opportunity to address a large need (Doksum, Joseph, Watson, Kim & Brand, 2004). Focus groups revealed a strong interest on the part of different racial and ethnic populations to learn more about genetics and its relation to health and disease (Catz, et al., 2005). March of Dimes (MOD), its national partners and HRSA agreed that community involvement was necessary in order to learn more about the cultural and language needs of diverse populations, and to address those needs adequately.

Community experts from the project's National Advisory Committee (NAC) recommended using Community-Based Participatory Research (CBPR) to engage diverse communities in a meaningful way. Building community partnerships is a key part of CBPR and ensures community involvement from the beginning of the project. Consumer participation would help ensure that the information gathered reflected the genetics education needs of the community.

Before MOD and its partners could move forward, they needed to assess their readiness to take on this project. An expert in CBPR was asked to present this approach to MOD, national partners, HRSA and the project's NAC. The group learned that this approach would require an organizational commitment to using participatory principles, patience, flexibility in planning and implementation, and resources to support capacity-building at the community level. MOD and its partners took the time to reflect on the magnitude of commitment and resources needed to pursue a community-based initiative at a national level. They concluded the following:

- MOD and its national partners were genuinely committed to serving the needs of underserved, diverse communities.
- MOD and its partners had the organizational support from each of their institutions to move forward because the project was in line with each of their missions.
- Through its local chapters, MOD had a history of working with diverse communities. Access to various communities could therefore be explored through existing chapter connections and through the project's National Advisory Committee.
- Though MOD had some knowledge of these communities, it understood that it would need to engage the key stakeholders and listen to how the community defined itself and its priorities.
- MOD and its partners were knowledgeable about genetics including the areas of newborn screening, research and ethical issues. They were willing to provide training and education so that community members could be equal partners in the research process.
- MOD and its partners could contribute staff time, financial resources, a national network for dissemination and technological resources.
- MOD and its partners were aware of the need to engage communities in a culturally sensitive manner and were open to learning and growing throughout the project in order to interact effectively with community stakeholders.

As a result of this self-assessment, MOD and its partners committed to using participatory approaches to engage communities in genetics education needs assessments. MOD would be guided by a community expert who was a skilled facilitator and leader in CBPR methods. The next step was to decide which communities to approach and to discuss the possibility of partnership. The project was named the Genetics Education Needs Evaluation (GENE) Project.

## STAGE 2: MOVING FORWARD – How to Approach and Involve Community Members

Once you have an understanding of the principles of a partnership and have assessed your readiness to work with the community, it is time to learn how to approach and involve community members. Stage 2 provides steps and tools to help you learn more about the community, engage key community leaders, and plan your first community meeting to gain feedback on your project. Identifying partners can be a daunting task. The following strategies will help you get started.

### Step 2.1: Identify the Community

#### What is a Community?

A **community** is a group of people with similar characteristics or a shared identity. Communities can be defined in geographic terms, such as people living in the same neighborhood or zip code area. Communities also can be defined based on information collected from the U.S. Census, such as race, ethnicity, culture, religion, political associations, education levels or income status. As you gather information it's important to understand how the community defines itself so that you share their view of what makes them a “community” (Wallerstein et al., 2005, p. 34).

Here are a few questions to keep in mind when defining the community:

- Who represents the community?
- Which individuals, agencies or organizations have influence in the community and what is their sphere of influence?
- Are key members community residents or do they work for community-based organizations?
- Whom does the individual or community-based organization represent or report to?
- Who has the time, resources and flexibility to attend partnership meetings and take responsibility for action items?
- Who is defined as “outside” the community and should not be invited to participate? (Flicker et al., 2006)

*It is important to keep in mind that no one organization or individual can represent an entire community.* To ensure a diverse and representative partnership, members should be recruited from various sectors of the community.

## Stage 2

### Moving Forward

—  
How to Approach and Involve Community Members

• Identify the Community

• Do Your Homework

• Connect with Community Gatekeepers and Key Informants

• Meet the Community Stakeholders

• Form a Partnership Planning Group

## Step 2.2: Do Your Homework: Get to Know the Community

### Assess Community Strengths, Assets and Resources

You may need to do some research to help you identify individuals and organizations interested in your project. Try to learn as much as possible about the community's strengths, resources, people, history, culture and leaders. Learning about the community before approaching individuals or groups shows that you are genuinely interested in the community and helps you gain local credibility. You may also gain a better sense of who might serve as possible community partners. (Wallerstein et al., 2005, p. 34-35).

You can get information about the community from the U.S. Bureau of the Census, the local planning department or the local health department. These resources can give you information about the makeup of the community, such as: age, sex, race, ethnicity, education, marital status, family composition, employment status, individual and household annual income, and individual and family poverty levels.

Information can be obtained from local libraries and academic institutions, or from other community-based organizations and groups. They can provide information about a community's history, where its residents are employed and who the key leaders are. For example, there may be an individual or community-based organization that serves as the community's voice on a specific issue. Involving community-based organizations may increase the project's success in reaching its target population and in sustaining its mission once the project ends.

Getting to know the community and how it works is an ongoing process that takes time and patience. Look to various community resources and sectors to understand the "make-up" of the community. You may identify and connect with community leaders in the following sectors or fields:

- Local businesses
- Schools and universities
- Local social organizations
- City/county government
- Law enforcement
- Health and medical professions
- Social services
- Mental health and treatment services
- Clergy or spiritual community and faith-based organizations
- Parent and youth groups

Adapted from *Community Readiness: A Handbook for Successful Change* (Plested, Edwards & Jumper-Thurman, 2006)





Look at the community's strengths and resources. Learn about issues that are important to the community members you will be working with. Check to see if partnerships already exist. If your group has worked with the community in the past, it's important to note what worked and what was problematic. Also note any lessons learned that may apply to this new partnership. Recognizing past problems and identifying strategies to overcome mistakes will help you and your organization build stronger partnerships.

Conducting an inventory of the community's assets and resources is an important step toward forming a partnership. As you gather information on the community's needs and assets, community priorities may emerge. Realize though that you cannot determine the community's true priorities without obtaining the community's perspective.

### Step 2.3: Connect with Community Gatekeepers and Key Informants

Entering a community about which you have limited knowledge can be daunting. One way to learn about and get involved with a community is to interview gatekeepers, key informants and stakeholders.

**Gatekeepers** are individuals who know the community, its issues and its players. They may also be leaders themselves and often influence community issues. Gatekeepers usually work in the community and are well-known and respected among community members and leaders. You can reach gatekeepers through existing networks that you or your organization have developed over time.

**Key informants** have spent enough time in the community to have gained special knowledge about the community. They are "thoughtful observers and informal historians" that can articulate important issues of culture, key groups and relationships, and perceived barriers. They at times may help facilitate health promotion efforts (Eng et al., 2005, p.89).

**Stakeholders** are those individuals or groups affected by the issue. A gatekeeper or key informant might also be a stakeholder.

If you don't know the community well, you can identify gatekeepers by "doing your homework," as described in Step 2.2. You can ask local community organizations to tell you who the individuals are who have influence in the community or are perceived to be community leaders. Usually they work in local neighborhood councils or community-based organizations (CBOs). You may find e-mail addresses or phone numbers through local agency listings. CBOs can also provide insight into whether your new initiative will drain or compete with any resources, talent and finances from the community. You can also learn whether CBOs have existing criteria for assessing their involvement in new partnerships. Still, it may be necessary for you to attend several local events to meet with and build new relationships with community members in person. At these



events, it is important to be respectful and observant of the culture and traditions of the community. Do not force your agenda, but take the time to get to know those who may be your future gatekeepers, key informants and stakeholders.

### Conducting Key Informant Interviews

Interviewing gatekeepers or key informants is a good way to learn about the community and brainstorm about possible partners. The benefits to conducting key informant interviews are listed in the table below.

#### Benefits of Key Informant Interviews

- Learn more about the community and key local groups and leaders.
- Express your interest in the community.
- Find out if there have been similar programs in the past and who in the community played key roles.
- Ask about the politics of the community, who gets along with whom, key concerns and problem areas, success stories.
- Learn about individuals and organizations working on similar issues.
- Familiarize yourself with other coalitions you might choose to join.
- Obtain support from the informant for your partnership.



## Strategies for a Successful Key Informant Interview

An interview is a conversation with a purpose. You can conduct an interview on the phone or in person. During the interview, you gather information to help you build the community partnership. It is important to prepare yourself before the interview. The checklist below provides some tips to help you prepare for and conduct a successful interview.

### How to Conduct a Key Informant Interview

#### Before the Interview:

- Gather background information on the issue to be discussed.
- Learn about the person and his/her organization.
- Write a list of questions to ask.
- Familiarize yourself with other individuals and organizations addressing the same issue.
- If you have a relationship with any existing gatekeepers or CBOs, ask if they can help in making introductions.

#### During the Interview:

- Introduce yourself and your organization using the suggested script below.
  - Explain the purpose of the interview.
  - Stress that you understand that s/he is an important community leader.
  - Give the name of the person who referred you to that person. This can help build trust and credibility.
  - Be honest, polite and to the point.
  - Be respectful of the person's time.
  - Explain the project, including:
    - An overview of the project
    - Who you represent
    - Information about funds, the funder and its expectations (if available).
    - Possible benefits to the community.
  - Ask if there are other people who may be interested in getting involved.
  - Ask who are the key stakeholders in the community, including:
    - Who is affected by the problem, issue or topic to be addressed?
    - Who will benefit from the partnership?
    - Who has worked on this problem before?
    - What are the resources that each person or group can bring to the project?
    - Who is well respected or well-known in the community?
  - Ask for help planning a community meeting so that you can get to know the community leaders recommended by your key informant.
-

### Sample Script for Beginning a Key Informant Interview

“Hello, good morning/afternoon! My name is [your name]. I work with the [name of organization]. We are developing a community program on [name topic]. We are in the process of getting to know the community and its leaders so that we can establish community partnerships. Your name was given to us by [name of referring community leader] because you’re a key community leader. I’d like to briefly describe the project, get your thoughts on it and find out if you are interested in working with us. Also, if you can suggest other people who might want to get involved, that would be appreciated. Is this a good time? [If yes, continue. If not, arrange for a follow up face-to-face meeting or conference call].

Key informant interviews help you identify key **stakeholders**. As mentioned before, stakeholders are the people and organizations in the community who may benefit from what you are trying to do. Stakeholders are those individuals or groups who are most affected by the problem you are seeking to address. Your key informant may help you identify stakeholders who have the potential to become community partners. The form below can be used to track a list of possible community partners and stakeholders. Keep this form on hand as you brainstorm ideas during your key informant interview.

### Community Partner Inventory Form

*Instructions: Use this form to list possible community partners/stakeholders.*

| Sector  | Name | Organization | Address | Telephone | Email |
|---|------|--------------|---------|-----------|-------|
| Health care<br>(hospital, clinics, physicians,<br>nurses, etc.) |      |              |         |           |       |
| Community-based<br>Organizations (CBOs)                         |      |              |         |           |       |
| Education   |      |              |         |           |       |
| Faith-based<br>Organizations                                    |      |              |         |           |       |
| Business  |      |              |         |           |       |
| Government Agencies   |      |              |         |           |       |
| Consumer Groups   |      |              |         |           |       |
| Other:  |      |              |         |           |       |
|   |      |              |         |           |       |

Possible community partners or stakeholders to consider include:

- Family members (parents, spouses and significant others) affected by the problem
- Health care providers such as primary care doctors, pediatricians, counselors, occupational/physical therapists, etc.
- Directors or staff of community-based human services organizations
- Local and state departments of health and human services
- Community members, leaders, outreach workers and concerned citizens
- Local chapters of national consumer advocacy organizations that may already be working in the community on similar issues
- Faith communities
- Schools and educators
- Staff from federal government agencies
- Policy-makers, including elected officials
- Community health workers (CHWs) or health promoters
- Other community leaders (informal and elected) interested in the topic in question.



## CASE STORY

### Leveraging Existing Connections to Explore New Partnerships

The March of Dimes, HRSA and the national partners had to decide quickly about whom to partner with on the new GENE Project. Due to time constraints, it was necessary to find communities that were already working on genetics issues or had community leaders that were interested in learning more about genetics. These communities also needed to be willing and able to start working on the project immediately. The GENE Project community demonstration sites would need to meet the following criteria:

- Designated as a medically underserved area
- Presence of a clearly identifiable racial/ethnic population
- Strong history in community organizing and mobilization
- Expressed interest in genetics education
- Interest in using a CBPR approach

The next step was to find out if project planners already knew of groups that fit the criteria. Several members of the GENE Project National Advisory Committee provided suggestions based on their personal experiences with various communities. Two advisory board members served as the initial links to two communities – Washington Heights/Inwood, NY, and Flint and Lansing, MI. With help from these key advisory board members, the March of Dimes set up face-to-face or telephone interviews with gatekeepers in both communities. One advisory board member connected the March of Dimes to a well-respected bilingual-bicultural Hispanic physician who served as the gatekeeper to the Washington Heights/Inwood communities. The

other advisory board member was the co-principal investigator for a genetics policy project, which addressed the concerns of the African American communities in Flint and Lansing.

Several key informant interviews were conducted. The March of Dimes Project Director shared information about the national organizations currently involved and the project's objectives. Key informants shared information about: (1) their involvement in the community; (2) their organization and/or community; (3) their opinion about whether or not genetics education would be interesting and relevant to community members; and (4) suggestions for other gatekeepers to contact. As a result of these connections, the March of Dimes was able to meet with representatives of the two community sites to explore further interest in the project.

Washington Heights/Inwood (WH/I), NY, is located on the northern tip of Manhattan. About half of the population is Spanish-speaking immigrants and predominantly of Dominican heritage. The community is known for its effective community organizing, history of coalition-building, and for the strengths of its community-based organizations. (Doksum et al., 2004, p. 38).

Lansing, the state capital of Michigan, is a diverse community that is home to Michigan State University. Flint is located about 45 minutes by car from Lansing, and is a city known for its auto manufacturing. Unemployment is widespread due to the pullout of several auto manufacturing plants, but the city retains strong civic and faith-based organizations. (Ibid, 2004, p.38).

## Step 2.4: Community Dialogue: Meet the Community Stakeholders and Possible Partners

Some key community members or leaders may help you plan a community meeting to share your thoughts about the project. These meetings are important because they allow you the opportunity to get to know other community leaders and to generate interest and support for the project.

The first community meeting is very important to the success of your project. Present a broad vision of the project. Be honest about what you would like to see happen and about what the project can and cannot do. Community leaders have long memories. They will hold you accountable if you make false promises.

*Most important: Listen carefully to community members as they discuss their concerns and priorities.* Do not dominate the meeting with a one-sided discussion of your agenda. Elicit feedback and seek collaboration; be flexible and consider alternatives.

By the end of the meeting you should have a basic understanding of the community's concerns and needs. You may be able to win the community's enthusiasm for and collaboration on the project. But don't be surprised if your individual vision for the project has changed by the end of the meeting. Together, the group should decide on the next step.

The checklist below lists planning tasks to help you organize your first community meeting.

### Community Meeting Planning Task List

- Prepare a list of individuals and organizations affected by the problems/project you are addressing.
  - Arrange a telephone call and/or face to face meeting to briefly explain the objectives of the project and of the community meeting. You may want a key informant to assist you.
  - Set a date for a community meeting with these individuals and other key community members.
  - Write an invitation letter stating the purpose of the meeting and what you hope to achieve. Include information about the meeting's date, time and location. You also can use a flyer, the internet or a phone tree. (See sample invitation letter below).
  - Prepare a written description of the project for discussion at the meeting.
  - Prepare an agenda. (See sample agenda below).
  - Prepare project fact sheets, information about the problem/issues, and any other information that will help others become knowledgeable and committed.
  - Arrange for food or snacks at the meeting.
  - Develop an evaluation form to gather feedback from meeting participants about what they thought about the meeting.
-

Below is a sample letter of invitation to mail, e-mail or fax to your guests.

### Sample Letter of Invitation

Name

Address

Date:

Dear \_\_\_\_\_ ,

You are invited to an important community meeting to discuss (*purpose of the meeting*). During this meeting we would like to explore the possibility of a partnership between (*your organization's name*) and the community. You have been invited because of your strong leadership and interest in the health and well-being of this community.

The meeting is scheduled to last about (*length of time*) and will take place at:

Date:

Location:

Time:

For your information, please find a description of the project and a draft meeting agenda attached.

Please confirm your attendance by calling (*Name*) at (*telephone*) or emailing (*email address*). We are looking forward to meeting you.

Sincerely,

*Co-signed by project organizers and community leaders or gatekeepers*

*(Adapted from Washington Heights/Inwood GENE Project)*



Here is a sample of an actual agenda that you can use to guide your community meeting.

## Sample Meeting Agenda

### Community Meeting Agenda

Date

Place

Time

- I. Welcome (Meeting Organizers)
- II. Introductions (Everyone)
- III. Purpose of Meeting
- IV. Overview of the Problem to Be Addressed
- V. Background and Rationale of the Proposed Project and Key Partners
- VI. Why Your Community
- VII. Nature of the Project Partnerships
- VIII. Questions and Answers
- IX. Summary, Next Steps and Follow-Up

#### Meeting objectives:

- a) Get to know community groups and leaders
- b) Describe the lead agency and its national partners
- c) Share knowledge about the problem to be addressed
- d) Provide the background and rationale of the project
- e) Convey the importance of the project to vulnerable and minority communities
- f) Discuss the proposed partnership
- g) Form a planning group and agree to a follow-up community meeting

*(Adapted from Washington Height/Inwood GENE Project)*

## Elements of a Successful Community Meeting

There are strategies you can use to help ensure a good meeting. Here are some suggestions:



- Have food or snacks for people to eat. Having food helps to create a warm and welcoming atmosphere. Serve food that is familiar to the people you are meeting with.
- Be sure that the person who runs the meeting (the **facilitator**) has good communication skills and knows how to work with groups. A good facilitator can run the meeting, foster discussion and resolve conflict in groups. He or she should create an environment that allows everyone to participate and should be skilled at redirecting the conversation away from people who tend to dominate the conversation.
- Structure the meeting and present your information so that it is interesting and compelling for those attending the meeting. Use the time to lay the foundation for the partnership. Encourage community members to feel a sense of commitment to the project and build upon the relationships of all those involved.
- Be prepared to answer questions about the project and discuss issues of concern to the community, including:
  - What are the benefits to the community?
  - Will the project compete with or build upon existing community priorities?
  - How much funding is available?
  - Who has ownership of the process?
  - What will happen after the project comes to an end?

## Step 2.5: Form a Partnership Planning Group

As a result of the first community meeting, a small group of individuals may emerge to form a partnership planning group. Sometimes a partnership is more effective when a small group from the community takes responsibility for some of the tasks. For example, a **Steering Committee** or **Community Advisory Board** of leaders or community residents may take responsibility for some of the first steps toward developing the community partnership. They can convene the community meetings, set the agenda, and focus the group on key issues. These issues include formalizing the organizational structure of the community partnership, and involving new and ongoing members.

## Challenges and Solutions to Involving the Community

The chart below describes some problems that you may encounter at the beginning of the project and offers possible solutions.

### Some Problems and Solutions to Involving the Community

#### Problems

Inadequate or no money and staff to complete project tasks

#### Solutions

- Find funding.
- Find existing in-kind resources in the community to complete tasks. (i.e. community experts, student interns, etc.)
- Build on existing resources to increase community capacity. Offer staff training and development opportunities.
- Identify consultants and/or subcontract with community groups to assist in activities.
- Create realistic goals and objectives that match available financial and human resources.

Heavy workload and lack of time to complete tasks

- Agree to a realistic and flexible work plan and timetable to complete tasks. Realize that timetables may change due to unexpected reasons.
- Divide tasks among partnership members according to their available time and resources.

Gaps in knowledge and skills

- Identify consultants and community members for help.

Negative relationship from the past between your organization and the community

- Discuss problems up front.
- Acknowledge your organization's previous history.
- Allow for an open dialogue and try to find creative solutions.
- Be patient, don't be defensive, and realize that it will take longer to gain trust and respect.
- Find common ground to get started.



## CASE STORY

### Meeting with the GENE Project Community Partners

#### Washington Heights/Inwood, NY

The first GENE project community meeting was held in Washington Heights/Inwood, NY. An expert in CBPR moderated the meeting, which helped to engage community leaders in the discussion. Some of the questions that the March of Dimes was prepared to answer included:

- Why should genetics be moved to the forefront of all the community's issues? Why is it important in the Hispanic community?
- How will this project affect other community projects?
- What will happen to the project after the grant is over? What will be the relationship between the March of Dimes and the community?
- How much commitment is needed to make the project a success?
- If families are educated about genetics issues, will services be in place to respond to people's questions and need?
- What would the community do with genetics information?

At the conclusion of the meeting, it was determined that the community was interested in exploring genetics education further. Two community leaders from the Dominican Women's Development Center (DWDC) and the Northern Manhattan Perinatal Partnership were nominated and accepted the positions of co-conveners for a new coalition on genetics education.

The Dominican Women's Development Center is a not-for-profit organization that provides multicultural and holistic social services, education, economic and cultural development programs to empower Dominican/Latina women and their families who reside in Washington Heights/Inwood and other New York City communities.

The Northern Manhattan Perinatal Partnership provides education and support services to the residents of Northern Manhattan to improve the overall health status of women, strengthen families and reduce infant and maternal mortality.

The group agreed to meet within one month. DWDC agreed to host the next meeting at their site and work with the March of Dimes to plan the logistics. The first item on the agenda would be an educational presentation on basic genetics.

#### Flint and Lansing, MI

The first community meeting was convened by the Co-Principal Investigator from the Communities of Color (COC) Genetic Policy Project, a coalition based out of Michigan State University. He invited members to assist in designing components of the newly proposed GENE Project. Now the **Principal Investigator (PI)** for the GENE Project, he shared the concept of expanding the existing COC coalition to include a school as well as another community-based organization. This provided the opportunity to engage another segment of the population – parents of children attending schools where genetics education could be provided. The PI shared the idea of having a community-based organization serve as the lead agency in the project, instead of the University. This would ensure that the program was coordinated from the community's perspective. The community partners welcomed this as a way to increase community capacity, leadership, and ownership for the research. The organization selected to be the lead agency was the Urban League of Lansing. The Michigan GENE Project's focus would be to assess the specific educational needs of African Americans about genetics.

The former COC representatives were excited to have the opportunity to continue and expand upon the work they had begun in their communities. As a result of the meeting, the group quickly formed a Community Advisory Board (CAB) to advise and participate in the needs assessment alongside the University. An evaluation team was also added to assist in evaluating the process. The evaluation team consisted of a University representative and a genetics educator. The Community Advisory Board (CAB) included: Alpha Kappa Alpha Sorority, Inc., Omega Psi Phi Fraternity, Urban League of Lansing, Woodcreek Elementary School, Greater Lansing African American Health Institute, Michigan State University, and two organizations from Flint – Faith Access to Community Economic Development (FACED) and the Urban League of Flint. The March of Dimes, Family Voices and Genetic Alliance were added as national partners. The CAB members agreed to assist the research team in engaging specific segments of the African American community to understand their views on genetics education through focus groups, dialogue groups and town hall meetings.

## Summary

This section described the process of involving “new” communities in partnerships. It highlighted the need to:

- a) identify and define the community you seek to engage
- b) learn about the community’s culture and norms
- c) identify possible partners
- d) conduct interviews with key people in the community
- e) plan and conduct the first community meeting to gain community feedback.

The next section will describe the steps to formalize and maintain your partnership.

## STAGE 3: PUTTING IT ALL TOGETHER – How to Formalize and Maintain a Community-Based Participatory Partnership

### Stage 3

#### Putting It All Together

How to Formalize  
and Maintain a  
Community-Based  
Participatory  
Partnership

- Define Your Partnership
- Develop an Identity and Purpose
- Build Group Composition and Leadership
- Create Structures and Guidelines

This section tells you how to create the structures to support and strengthen your partnership goals. The figure shows you the key steps in Stage 3 to help you formalize and maintain a partnership.

### Step 3.1: Define Your Partnership

#### Types of Partnerships

There are many types of partnerships. The type of partnership a group chooses is determined by how people choose to work together. The process of partnering is built along a continuum. A group may begin informally and then grow into a more formal partnership with clear goals, objectives and rules. The type of partnership you choose depends upon the group's goals, setting, organizational readiness, level of commitment from members, and the extent to which barriers of time, trust and turf can be overcome (Himmelman, 2002). Below are several types of partnerships you might consider for your project:

**Advisory Committees** respond to organizations or programs by providing suggestions and technical assistance.

**Commissions** consist of citizens appointed by official bodies to develop or review policies.

**Consortia and Alliances** are semi-official membership organizations. They typically have broad policy-oriented goals and may span large geographic areas. They usually consist of organizations and coalitions rather than individuals.

**Networks** are loose-knit groups formed primarily for the purpose of resource and information sharing.

**Task Forces** come together to accomplish a specific series of activities, often at the request of an overseeing body.

**Coalitions** are organizations that are made up of various organizations working together for a common purpose.

(Cohen, Baer & Satterwhite, 2002, pp.161-178; Himmelman, 2002)

In the area of public health, numerous coalitions have been developed to address various community health problems. The following section will briefly describe the benefits of a coalition and the reasons why organizations or individuals form or join them.

## Benefits of Forming a Coalition

Coalitions have proven to be effective ways of mobilizing and organizing community members to address issues of common concern. The reasons why individuals and organizations form and join coalitions are listed in the table below.

### Reasons to Join or Form a Coalition

- Interest and commitment to community issues.
- Feel that group goals are achievable when working with others.
- Perceived benefits (access to information or technology, increased visibility, networking, financial resources) to participating in the partnership.
- Desire to work with agencies with greater expertise or complementary knowledge and skills.
- Want opportunities to share resources and reduce the amount of competing services.
- Gain credibility from their association with other stakeholders.
- See the value in working with multiple groups to increase influence and negotiating power with other public and private groups.
- Chance to increase and improve community resources and services.

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(Berkowitz & Wolff, 2000, p. 2)

Coalitions can be short-term or long-term. A short-term coalition is usually formed to address clear-cut issues that require immediate action. They tend to end when the short-term goals have been achieved. Long-term or permanent coalitions require the development of clear goals and objectives, formal organizational structures (for example, an executive committee), written rules and regulations (for example, bylaws and membership criteria), staff and the delivery of concrete services if funding is available (Ibid).

## Roles in a Partnership

Individuals and/or organizations often play distinct roles in a coalition. Roles are usually not mutually exclusive and often overlap. One individual organization might fill several roles. Below are some common roles played by organizations and individuals in a partnership.

## Common Roles Played by Organizations

**Convener:** Leads a highly visible public discussion of community issues in order to highlight a common understanding of the issues.

**Catalyst:** Stimulates discussion with a longer-term strategy in mind.

**Conduit:** Acts as the lead agency in providing funding and administrative oversight for local collaborative projects. May overlap with role of Funder.

**Funder:** Provides public and private funds to support the project; may choose to be involved in the design and planning of the project.

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(Himmelman, 2002)

## Common Roles Played by Individuals

**Chair:** Acts as the key leader and spokesperson for the coalition; may sign letters and other official documents, testify in court, etc.

**Facilitator:** Runs the coalition's meetings; fosters group discussions; resolves disagreements in the group.

**Individual member:** Does not represent a specific organization within the coalition.

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(Cohen et al., 2002, p. 161-178)

## CASE STORY

### The Beginnings of the WH/I GENE Project Coalition

Within a week of the first community meeting, the co-conveners of the new coalition set up a Planning Committee. The group decided to form a genetics education coalition because of the community's expertise in coalition-building and their commitment to creating a structure that would last beyond the length of the grant. The hope was to apply for 501(c)(3) status in the future and become another invaluable resource to the community.

DWDC, with support from its community partners, served as the coalition's fiscal conduit. The March of Dimes, and the GENE Project national partners, Family Voices and Genetic Alliance, sent staff to attend the coalition's monthly meetings to serve as coalition members, and also provided technical assistance and training on genetics and ethical issues. Individual members from the community and

representatives of community-based organizations CBOs served as active participants in the coalition's decision-making process. CBOs rotated the responsibility for hosting community meetings and were compensated for their efforts through mini-grants.

Some funds were also used to hire a full-time coordinator to work for the coalition. As the partnership developed, the project moved quickly into the research training and data collection phases. The March of Dimes arranged for a consultant with expertise in community-based participatory research (CBPR) to serve as a facilitator and provide technical assistance and training to community members so that they could become active participants in the research process.



## Step 3.2: Develop a Partnership Identity and Purpose

### Vision, Mission, Goals and Objectives

A key part of coalition-building is to create a shared **vision**, **mission**, **goals**, and **objectives**. These are created in cooperation with all group members.

A **vision** communicates what the organization believes are the ideal conditions for the community and how things would look if the problem was addressed. Visions are usually expressed in a vision statement. Vision statements are usually understood and shared by members of the community; are broad enough to allow diverse local perspectives to be encompassed within them; are inspiring and easy to communicate.

A **mission** describes what the group or organization is going to do and why it's going to do it. Mission statements are similar to vision statements but they are more concrete. Mission statements are concise and outcome-oriented.

**Goals** are “action-oriented” and defined as the ideal outcomes the organization hopes to achieve. They are expressed as general statements that say what the organization hopes to accomplish, the type and amount of change it wants to take place, and how long it should take to make the change.

**Objectives** are the specific strategies and tasks that will be used to reach one's goals. Objectives should be SMART:

- S** Specific
- M** Measurable
- A** Achievable
- R** Realistic
- T** Timed (has a deadline or timetable attached to it).

(Nagy & Fawcett, n.d.)

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**“Partnership begins with communication that facilitates relationship building that leads to trust, understanding and common vision.”**

**E. Yvonne Lewis, Michigan GENE Project**

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The overall vision of the GENE Project was to create a collaborative network that would develop and disseminate culturally sensitive genetics information. This information would encourage individuals to ask more questions and make better informed decisions about their health. Even though there was a set vision for the GENE Project, each community identified specific mission, goals and objectives that made the project their own.

### Washington Heights/Inwood GENE Project Coalition

**Mission:** The WH/I GENE Project Coalition is a network of community residents, educational institutions, local businesses and human service organizations committed to improving the health and social well-being of the entire community, initially concentrating on the Latino population, through community genetics education, and by increasing access to high quality, linguistic and culturally appropriate genetic services.

**Goal:** To develop and implement community-based participatory consumer genetics education initiatives.

**Objectives:**

- To engage GENE partners and a core group of community-based organizations, including health and social service agencies, to form a coalition with clearly stated mission, purpose, goals, objectives and structure.
- To identify community needs, resources, barriers and accessibility to genetic services through knowledge-based questionnaires and focus groups.
- To identify training activities related to program goals and objectives.

- To develop, test and disseminate culturally appropriate human genetics messages that would assist community members and groups in making inquiries and informed choices about health.

### Michigan GENE Demonstration Project

The ultimate goal of the MI GENE Demonstration Project was to develop a model by which national genetic advocacy organizations could collaborate with African American community-based organizations to provide culturally appropriate genetics education and services. The project's goals were to:

- Collaborate with community-based organizations (CBOs) to engage African Americans of diverse socio-economic levels in the process of community dialogue on issues related to genetics education and genetic services.
- Identify barriers preventing national and state genetics organizations and networks from effectively interacting with African American communities.
- Recommend strategies that would facilitate attainment of genetics education and access to genetic services.
- Identify a model of community-driven dissemination of genetics information to meet the target population's needs.
- Develop a framework for understanding genetics and genetics education across the life span in the African American communities of Flint and Lansing, MI.
- Develop sustainable genetics education initiatives through community engagement.
- Develop a process where the Michigan partners and community participants are recognized for their contribution to community-based genetics education.

## Group Name and Logo

Selecting a name and logo for the group is an important group process that provides a sense of identity and ownership. One way to choose a group name is to have participants brainstorm and list possible names. From this list, the group can come to a consensus on one or two names. The group name and a logo usually can be decided during a coalition meeting. It is important to ensure that the name and logo are not already being used by any other organizations; otherwise, you may be need to consider other options.

### CASE STORY WH/I and MI GENE Project – Group Identity

The process of selecting a group name and logo helped each of the GENE Project communities to create a sense of identity and unity. In Washington Heights/Inwood, NY, the new coalition progressed fairly quickly towards deciding on a coalition name and mission, which propelled them to begin developing their bylaws and coalition infrastructure. There were several coalition meetings held to discuss whether the coalition should focus on the needs of the entire Washington Heights/Inwood community, which was extremely diverse, or if the focus should remain on the Hispanic/Latino population. Because of limited resources and limited time, the group agreed to focus on the needs of the Hispanic/Latino population and once a model for genetics education was developed, to apply for additional funding that would address the needs of the other ethnicities and minorities in the community.

One of the first tasks was to reach out to recruit new members and increase awareness of the project. To do this, the coalition needed to develop literature such as flyers and brochures. The coalition discussed the image that it wanted to convey to the community. Members of the coalition wanted the community to know that the local project was led by a community-based network of organizations and individuals who had their best interest in mind. They wanted the community to know that this project would eventually benefit their children and families. Existing coalition members solicited photographs from actual community residents who gave consent to the coalition to use



their photos in their materials. As a result, the coalition developed a recruitment flyer (see Appendix B1) that reflected the “face” of the community and made its members proud.

The next task was to develop a logo that represented the purpose of the coalition. A coalition member’s brother contributed his time and talent as a graphic artist to develop a design that was approved unanimously by coalition members.

The Michigan GENE Project communities also went through a similar process of developing their logo and identity. The group agreed to name their project the Michigan GENE Project Demonstration. It turns out that their project coordinator was a talented, aspiring artist who developed the logo for the group.

## Step 3.3: Build Group Membership and Leadership

### Recruiting and Maintaining Members

One of the biggest challenges in establishing CBPPs is to recruit and retain members. The table below offers strategies to help you find and involve community members. Be sure to include a diverse group of individuals who will contribute their different experiences and expertise so that the group's composition offers balanced points of view from different sectors. Use education materials that are sensitive to the cultural and language needs of the intended community to attract new members to your partnership. You can use the sample membership form in Appendix B2 to track your membership.

You can use the Meeting Minutes Template in Appendix B4 to track attendance and minutes of the meeting. The attendance sheet and minutes show how involved group members are in different activities. It also can help identify those who aren't attending and may be losing interest.

### Strategies for Recruitment & Maintaining Membership

#### Recruiting Members

1. Conduct face-to-face or telephone interviews with community residents and leaders identified by gatekeepers.
2. Invite community members to partnership meetings and discussions.
3. Ask "new partners" to help identify other community members to ensure a diverse group.
4. Create an attractive recruitment flyer or brochure to distribute and post at community events (See sample Recruitment Flyer, Appendix B1.)
5. Use a Membership Form (see Appendix B2) to track who is participating in the group and what kind of experience and expertise they bring.
6. Hold meetings at convenient times and locations. Address barriers to attendance such as childcare and transportation.

#### Maintaining Members

1. Create a warm and friendly meeting environment.
2. Provide clear information about group goals, objectives and action steps.
3. Provide meaningful opportunities for new and old members to get involved, connect with one another and build trust.
4. Keep a record of who attends meetings and how to contact them again.
5. Use evaluation forms to gather feedback about how meetings are run. (See Meeting Evaluation Form, Appendix B3.)
6. Establish a good communication system. You can:
  - a) Send out regular mailings about group activities and future meetings.
  - b) Create a Website or listserv to send messages to the membership.
  - c) Establish a phone tree and ask members to contact and remind other members to attend group meetings and/or activities.
7. Plan social events to build strong personal ties between members.
8. Involve as many members as possible in the planning and implementation of group activities. Try to plan some activities that will result in short-term, concrete results.

A warm and friendly atmosphere and involvement in meaningful activities helps in recruiting and retaining members. It is important for the group to achieve concrete results so the members can feel a sense of accomplishment and that their time was well spent. An evaluation of group meetings by members can provide additional insight into how the group is progressing. (See Sample Coalition Meeting Evaluation Form, Appendix B3). This information can be used to improve group activities, run meetings more effectively and improve group meeting atmosphere.

Gradually the group members will develop strong personal ties among themselves. This personal connection serves as the “glue” that keeps the group together. However, in some cases, the group becomes so “close knit” that it does not necessarily seek or want new members. This may represent a challenge to the group. A close-knit group has a strong bond due to its members’ common history of working together. Though this bond facilitates ongoing communication, honest discussions on critical issues and decision-making, new members may feel unwelcome because they are viewed by the older members as disruptive to the group process. In most cases, however, new members are made to feel welcome in many group settings. Be sure to take steps to include new members and help them feel comfortable. New members can bring refreshing ideas and perspectives, make the group more vibrant and increase group productivity.

## **Group Leadership**

Effective leadership is key to ensuring a successful partnership. Several leadership skills are listed below so that you can match these skills to those individuals whom you would like to lead your group.

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**“Great leaders . . . cut through  
argument, debate and doubt  
to offer a solution  
everybody can  
understand”**

**Berkowitz and Wolff**

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A leader has:



- **Good communication skills** – Effective leaders know how to listen closely to the needs and concerns of community members, and communicate clearly and honestly.
- **Strong group process skills** – Competent leaders know how to build commitment, facilitate group discussions, encourage participation, create consensus, and move members toward achieving common goals. They tend to have experience leading groups in the past.
- **An ability to take action** – Good leaders know when and how to make decisions once member input has been sought, and can get things done quickly and efficiently. This helps group members feel that they are making progress to reach their goals.
- **A clear vision** – The partnership may need leaders who can move the group forward based on a shared vision. Good leaders can effectively communicate this vision to group members. These leaders can suggest creative solutions, new directions and possibilities.
- **Flexibility** – Strong leaders are open to new approaches when needed and don't get stuck in conflicts.
- **Honesty** – Leaders speak openly and candidly with the group. They take responsibility for their mistakes and the group's mistakes.
- **Ability to motivate others** – Good leaders know how to get others to work on the team.
- **Optimism** – Good leaders believe in the goal and have confidence that the partnership members will reach their goal.
- **Patience** – Good leaders understand that it takes time and patience to achieve goals.
- **Respect** – Good leaders show respect for others and expect partnership members to do the same.

Groups often have formal leaders who are elected by members or appointed to the position. They may have titles such as chair or president. Informal leaders may not have official titles or roles, but they can be very valuable. These are people who know how to bring community members together, have a history of community involvement, are respected by their peers, and are a strong influence in the community. Different leadership styles can affect group dynamics, relationships between members and the level of work that can be completed. It is important to select a leader who can build trust and consensus as well as move the group forward. “Great leaders are almost always great simplifiers who cut through argument, debate and doubt to offer a solution everybody can understand” (Berkowitz & Wolff, 2000, p.2).

Often times, consumers may find themselves in a new leadership role, especially in community-based coalitions or partnerships. The 12 Fundamentals of Practice developed by the Health Resources and

Services Administration can guide consumer leaders in their new roles or individual community members who are part of a new coalition (Health Resources and Services Administration, 2005). They are listed in the table below.

## 12 Fundamentals of Practice for Consumer Leaders

1. **Above all, be true to yourself.** Know your values, and be guided in all things by your own conscience. If you encounter situations that threaten your personal moral code, act in ways that are consistent with your own principles.
2. **Respect yourself; respect others.** Don't stretch yourself too thin. Define and maintain your boundaries. Look for the best in others; listen to their opinions and perspectives.
3. **Keep confidences.** Share confidential information only when necessary to prevent injury or death. Take care when telling stories about other consumers that neither the details nor the context of the story identifies that person. Ask permission from your own family and friends before sharing information about them.
4. **Honesty is the only policy.** If you or your family will benefit financially from engaging other consumers in activities, disclose that information. Never use your relationships with others for economic or personal gain. If you have financial or personal interests that could affect decision-making, disclose that information or excuse yourself from participation in voting or discussion of any issues that could pose a conflict of interest.
5. **Be transparent in your communication.** Give honest, clear and objective information to others. Disclose any limitations that are imposed on you about sharing information. Recommend alternate sources for information gathering.
6. **Name the hat you are wearing.** Make it clear if you are speaking only for yourself, on behalf of other consumers or for your organization.
7. **Share the wealth.** Be generous with the knowledge, opportunities and resources you have to help other consumers.
8. **Remember why you are there.** Take time to reflect on the unique role you play. Be true to those you represent.
9. **Take responsibility for yourself in the workplace.** Before you go to work for an organization, talk to your potential employer about the difficulties that might accompany the job. Be sure to determine:
  - What information can and cannot be disclosed to consumers and other clients of the organization
  - What level of advocacy you can engage in without fear of repercussions
  - What kinds of accommodations can and cannot be made for your special circumstances (e.g., health care and other need)Once you have been hired, learn the organization's policies, procedures and rules of the workplace.
10. **Be impeccable in your conduct.** Maintain the highest standards of professional and personal behavior.
11. **When in doubt, admit it.** Be truthful about your own skills and abilities. Take responsibility for informing others when you need additional support and training.
12. **Stay connected.** Maintain contact with other consumers in similar positions for purposes of support and information sharing.



Adapted from Rules for the Road: A Handbook for Consumers in Leadership Positions (Health Resources and Services Administration, 2005)

## Group Trust and Cohesiveness

Developing trust among group members and their leaders is critical to the survival of any group. This process is ongoing. A number of factors may affect the cohesiveness and degree of trust in a group. These include members' past history of working together, the pre-existing personal relationships of its members, members' experience working with groups and the willingness of the participants to share power. Once trust develops, it is easier to complete tasks and to meet objectives. However, when trust does not exist, meetings take longer, building consensus is more difficult and tasks may not get done on time.

Individuals, agencies or organizations often come to a group with expectations of what they would like the group to achieve. Members may at times be open about these expectations in order to influence others to move in the same direction. At times, however, these expectations are concealed as "hidden agendas." Hidden agendas can threaten the group's unity and interfere with the development of common goals and objectives. A **facilitator** can be helpful in encouraging trust among members by creating an environment where members feel safe sharing their needs and expectations with the group.

In a successful partnership, each partner makes a contribution to the group. Some partners may offer their time, energy and ideas while others may contribute funds, office equipment, computer technology or technical assistance. All contributions should be acknowledged, and each member should be made to feel valued by the group.

Trustworthiness and respect need to be demonstrated throughout the life of the partnership. The simple act of allowing others to finish their sentence or thoughts without interrupting, or following through on an action item you committed to doing can earn the group's trust and respect. A code of confidentiality should be adhered to in cases when personal or sensitive matters are discussed. You may also build trust and friendship by participating in activities that may not be directly related to the work of the project. For example, you may attend a health fair or assist a community partner in writing a proposal for another grant to help them sustain their community activities. At some point in the relationship-building process, a small tour of the community can be arranged by a gatekeeper to educate the other members of the partnership on the community's history, culture and environment (Wallerstein et al., 2005, p. 60).





## CASE STORY

### Group Trust in Flint/Lansing, MI

Trust is a critical element in developing and sustaining partnerships. Most of the Michigan Community Advisory Board (CAB) members trusted each other due to a previous working history. Individuals also had collective trust from and among community members. Historical trust based upon previous relationships, as well as a commitment to the issue for long-term change and involvement was an essential element to moving the project along.

However, trust needed to be developed between the MI CAB members and their new national partners. Many of the CBOs involved in the MI GENE Demonstration Project had not worked with the March of Dimes, Genetic Alliance and Family Voices before. In-person meetings offered the best opportunity to build relationships, but they were few and far between. Mistrust and tension were present at these meetings. However, each party tried to resolve these issues through continuous dialogue and clarification of roles and responsibilities. What helped the project move forward throughout these challenges was the personal relationships some of the MI GENE CAB

members developed with representatives from the March of Dimes and its national partners. A key turning point was when the national organizations were invited to present their organizations' missions and activities to the CAB at a special meeting in Flint, MI. Though this meeting occurred late in the project, it was instrumental in creating the "glue" between core CAB members and representatives from the national organizations.

Another way to enhance community relationships was to co-host grant meetings, which rotated between Michigan, New York and Washington, DC. Every effort was made to make sure that the meetings were run in a participatory manner with community input. The MI GENE CAB arranged tours of their cities, meetings with local community members, and delicacies from local caterers. The March of Dimes and the national partners also responded to the CAB's training and education needs by providing technical assistance when requested. It was a gradual transition before the MI CAB members could call the national organization true project "partners."

## Step 3.4: Create Organizational Structures and Guidelines that Support the Partnership

### Establish Group Rules and Structures

An important task of any group is to develop and agree on a set of rules to guide its work. Frequently these rules are established during brainstorming sessions at community meetings. Permanent or long-term coalitions often develop a corporate structure which requires bylaws to guide their efforts. **Bylaws** state the mission, purpose, goals and objectives of the coalition and list the group's rules. They also set out the roles and responsibilities of members, define the organizational and operational structure and establish meeting rules.

In addition to developing group rules, you may need to develop a simple structure to guide the group's work. This could be a board of directors, an advisory board or standing committees. If funding is available, you may want to hire staff to lead the project. If you have limited funding, it may work best to have community-based organizations take turns leading the group.

Below is a checklist of items that you may want to include in your bylaws.

### Bylaws Checklist

*Use this checklist as a guide. You can adapt or expand these components for your coalition.*

— **Name and Jurisdiction**

Defines the official name of your organization and the area that your group represents.

— **Vision, Mission, Goals and Objectives**

Defines your coalition's purpose.

— **Membership**

Explains membership criteria and member rights and responsibilities.

— **Governing Structure**

Explains the governing bodies and the process for making decisions. In this section, you may want to cover the following topics:

- Election of executive committee
- Establishment of board of directors
- Roles and responsibilities of program committees
- Voting procedures
- Resignation process
- Length of term of elected positions
- Amendment process

— **Meetings**

Defines criteria for meetings. In this section, you may want to cover the following topics:

- How often will the coalition and committees meet
- Who will facilitate the meetings
- Who will keep minutes of the meetings

— **Coalition Staff**

Explains procedure for hiring staff and staff functions. In this section, you may want to cover the following topics:

- Reasons to terminate staff
- Who shall determine staff qualifications

— **Funds Management**

Explains management of funds and the budget. In this section, you may want to cover the following topics:

- Who is responsible for distributing funds
- How one can submit a request to receive funds
- Whether or not the budget is public
- Fiscal year
- Financial reporting process

Source: Hampton, C. (2003). Writing Bylaws. Retrieved July 26, 2007, from <http://ctb.ku.edu>

## CASE STORY

### WH/I GENE Coalition – Executive and Standing Committees

Over the next few months after the initial community meeting, the March of Dimes worked with the WH/I GENE Coalition to develop the infrastructure for the new initiative. DWDC worked with community-based organizations (CBOs) to rotate and co-host monthly coalition meetings. These CBOs also recruited their constituents once the community needs assessment began. Meetings were held during lunch, and food was provided. Compensation was given to community members with young children for childcare expenses. The coalition also felt that it was important to hire a translator so that Spanish-only speakers could fully participate in the meeting discussions. In the first five months, the coalition established a membership list and several working committees:

- **Executive Committee** – Served as the coalition’s decision-making body. Met at least once a month to discuss, review and plan coalition’s activities and operations including monthly meeting agendas, presentations and sub-committee activities. Consisted of the coalition’s co-conveners and chairs of each sub-committee.
- **Needs & Assets Assessment Committee** – Led the community assessment activities using CBPR methodologies.
- **Community Awareness and Education Committee** – Collected, developed and disseminated educational materials about genetics. Developed and implemented a strategy to educate consumers in the community, including the use of the media.
- **Training and Education Committee** – Identified training needs and arranged educational sessions on human genetics for coalition members. Recruited local healthcare professionals, the March of Dimes staff and other national partners to provide the trainings.
- **Infrastructure Committee** – Developed rules and regulations (bylaws), addressed coalition needs in the areas of staffing, management, membership, sustainability and project logistics. Led by the coalition’s co-conveners.
- **Evaluation Committee** – Developed and implemented an evaluation plan of coalition activities.

### Develop Systems for Communicating and Decision-making

Another critical part of successful community partnerships is an effective communication system among members. Communication should be clear, honest and ongoing. Regular general membership meetings as well as task-oriented committee meetings keep members involved in the group process. Be flexible about meeting times to accommodate members’ work and family schedules. Hold an early morning breakfast meeting or a short after-work meeting. Meeting locations should be easy to get to and centrally located.

You may also want to develop a membership listserv to share information via e-mail and a database of members with contact information for regular mailing of information. Keep in mind that some members may not have access to computers or e-mail. Phone trees in which members are asked to invite three to five members to the upcoming community meeting are also helpful and actively involve members in the process.

Use an agenda and meeting minutes to serve as an official record of the group’s activities and decisions. Remember that those who put together the agenda may have more control over what is discussed at the meeting. Make sure to build in time for “new business” or questions and answers.

Distribute the agenda in advance to obtain feedback so that there is equal and fair participation in the group process (Becker, Israel & Allen, 2005).

An effective communication system relies upon a clear understanding of each person's role and function in the group, who makes decisions on behalf of the coalition and in what instances members should be consulted. A Decision-making Framework is provided in Appendix B5 to help you think about the types of decisions that may need to be made and the persons or bodies of individuals to be responsible for making them (Giachello, 2003).

## CASE STORY

### Modified Consensus in Flint/Lansing, MI

The MI GENE Project Community Advisory Board (CAB) members made decisions based on group consensus. Sometimes all voices were not at the table when decisions were made; however, those that were present were able to move the project along. This was possible because of the trust that was already established between existing CAB members. When community members could not be present, there was communication before and after meetings to make sure that the missing CAB members could voice their opinions and support before a final decision was made. The consensus model provided the group a means to continue its work even without quorums or a more formal decision-making process.

However, there were some challenges. Staff representatives from community-based organizations and academic partners changed and created some tension. During this transition time, there was lack of representation from certain groups, and the CAB could no longer benefit from the insights and expertise of some partners. In addition, some decisions were made on behalf of the community without full knowledge of all members. This created some discomfort and lack of trust, which hampered the project's progress. The CAB members were able to overcome these challenges because of the strong relationships that already existed, and the willingness of all CAB members to learn from and work with each other to meet the project's goals.

### Develop Partnership Guidelines

Partnership guidelines should be developed to help guide the process, clarify goals, and establish roles, responsibilities and expectations of partnership members. The document may describe how a new person or group can join the partnership. It can also describe the framework for dealing with future conflicts or challenges. Revisiting these guidelines or procedures every so often can help resolve conflicts. The list below suggests components you can include in your guidelines.

A more formal agreement can be created to outline how financial resources will be shared with participating community-based organizations (CBOs). This can be done through a **contract** or **memorandum of understanding (MOU)**, which are documents that describe the partners' involvement and participation, the nature of the project, the agreed-upon scope of work, the specific products or deliverables, a project time table, and may at times state the amount of funding available. The format of any formal agreement largely depends on the choice of the organization that is providing the funds. At times,

projects may have contract agreements or MOUs with multiple community-based organizations (CBOs). At other times, they may have a contract agreement with one main organization that then subcontracts with other groups. The latter option reduces the amount of bureaucratic paperwork and the delays common in large academic/research institutions (Rabinowitz, n.d.).

### Partnership Guidelines Checklist

*Below is a list of items that you may want to include in your Partnership Guidelines. These items can be adapted or expanded to meet your partnership's needs.*

— **General Information:**

- Purpose of the document
- Brief history and description of the project
- Definition of partnership principles
- Describe type of partnership and its mission, goals, and objectives
- Resources of partners

— **Roles and responsibilities of:**

- Organizational and individual partners
- Funders
- Evaluators
- Consultants
- Advisory committee

— **Communication Plan (ensures clear communication and participation between partners):**

- Regular meetings
- Conference calls
- Minutes of meetings and conference calls
- Decision-making (who makes decisions regarding roles and responsibilities of partners)

— **Dissemination Plan (sets guidelines for communication to an outside audience):**

- How to make information available to public (for example, press releases, websites and other media)
- Standardized acknowledgement
- Guidelines for future use of information
- Ownership of data, if any
- Authorship guidelines
- Media and public meeting guidelines
- Presentation guidelines

Since the March of Dimes was the recipient of the HRSA-funded cooperative agreement, it was responsible for contracting with the national partners, consultants and the fiscal agents at each of the community demonstration sites. Formal contracts were created with Michigan State University and with the Dominican Women's Development Center to lay out project deliverables and funding arrangements. Each organization was then responsible for subcontracting or granting funds to their community partners.

A partnership arrangement was created later to clarify the relation between the March of Dimes and the national partners, between the March of Dimes, the national partners and community sites, and be-

tween the two communities. Roles and responsibilities were outlined as well as a definition and principles of partnership that would guide the group's process. Strategies for dissemination and communication were also included. For example, a standard acknowledgment statement was created to recognize all partners in publications and presentations. Authorship guidelines and recommendations for the usage and ownership of data were also essential components of the partnership guidelines. The project partners took one whole day to meet face-to-face to sort out the nature of their relationships and to come to consensus. The partnership arrangement required continuous dialogue and was updated throughout the project.

## Challenges and Solutions to Maintaining Community-Based Participatory Partnerships

You will face a number of challenges as you build your partnership. Try not to get discouraged. Challenges are a normal part of the process of building something of value. In the section below, some of the common challenges you may encounter in building a partnership or coalition are discussed.

### Failure to Act

Some partnerships spend too much time on discussion and planning and not enough time taking action. Coalition members like to see the tangible results of their efforts. When there are no visible results, members may become discouraged and concerned about wasting their time. Be accountable for your actions. Meeting minutes can be shared with the members to serve as a record for what decisions have been made and what work needs to be done, eliminating confusion and misunderstandings.

### Limited Resources

All groups have limited resources, such as time, staff, and money. Many effective partnerships do not need much money, especially when they are just forming. But most groups require investments of time, a valuable commodity which is in short supply. Try to respect the contribution of time that participants make. Create realistic work plans that fit with participants' schedules. Volunteers sometimes cannot complete the work they agree to do. Problems can be avoided by setting realistic goals and having realistic work plans. As partnerships grow, they sometimes face complex and demanding problems that volunteer members cannot solve without help. When this occurs, it may be necessary to hire full- or part-time staff for the partnership.

## CASE STORY

### Clarifying Needs and Expectations in WH/I, NY

One major challenge that came up during the early stages of the WH/I coalition was the issue of time. The March of Dimes was concerned that the process of forming the coalition was moving too slowly. March of Dimes staff set up a meeting with the co-conveners to clarify the roles and responsibilities of the March of Dimes and community members. They met at a Dominican restaurant in Washington Heights. Each party openly discussed their concerns. As a result of the meeting, the coalition co-conveners and the March of Dimes were more confident in the relationship and in the progress that had already been made to move the project forward. The March of Dimes

learned more about what had been accomplished during the first few months to establish this new coalition. The March of Dimes also learned to step back, appreciate the community's expertise in coalition development, and acknowledge the time that community members were putting into a project on top of their primary jobs. In turn, the co-conveners appreciated that there was a bigger picture to keep in mind. They understood the need for a disciplined approach in order to achieve their goals in the remaining years. The meeting was an important step in solidifying the partnership between the WH/I GENE Coalition and the March of Dimes.

### Group Dynamics

The behavior of just a few people in a partnership can greatly influence the dynamics of the entire group. It is not uncommon for conflicts to arise among members over turf, leadership, scope of work and the nature of the group's membership. Conflicts also may arise over how decisions are made, how information is shared or simply because of a miscommunication. These conflicts can lead to divisive power struggles within the group. "Though conflicts are inevitable, effective resolution of conflicts may strengthen the partnership as partners demonstrate commitment to each other and to mutual goals" (Wallerstein et al., 2005, p. 46). "Conflict is a necessary part of group process. When welcomed and addressed, decisions are more creative and effective" (Becker et al., 2005, p.65). Potential conflicts can be anticipated and a process of resolution can be outlined in the partnership's guidelines. For example, in some cases the group may "agree to disagree" or a decision can be made by consensus rather than a majority vote.

A skilled internal group facilitator may be able to resolve some conflicts within the group. Other conflicts may require the help of a mediator, someone outside the group. Facilitators may choose to help the group stay focused on the main goal rather than address the conflict directly. This strategy can be helpful in a group that tends to focus too heavily on its internal, day-to-day operations rather than on long-term goals and issues of group process. However, bear in mind that each partnership is different and requires an individualized approach to problem solving and conflict resolution.

### Power Relationships

Community-based participatory partnerships are built on the principle that every member is valued and has something to contribute. However, some partnerships suffer when members have unequal power. A

perception may run through the group that some people are “insiders,” while others are “outsiders.” There also may be the sense that some people have more power or influence than others. Power inequities can take place due to differences in levels of education and income as well as other reasons.

Though community members may be very knowledgeable about their neighborhood, they may also distrust “experts” offering help. Similarly, “experts” may believe that they know best how to solve community problems. Sometimes they fail to respect the knowledge and opinions of community members. “Group effectiveness is improved when power is balanced, based on competence, expertise and information” (Ibid, p.64). If influence is skill-based, these skills and knowledge can be transferred to other members of the partnership through training, education and technical assistance.

### Cultural Differences

Although community-based participatory partnerships are based on the principle that everyone in a group is equal, inequalities are a part of life and often emerge within the group. These inequalities include racism, sexism and other forms of intolerance. Issues related to the imbalance of power, stereotypes and prejudice can hurt partnerships.

Communities are made up of people from diverse backgrounds. CBPPs are diverse by nature. Diversity can strengthen community partnerships. An effective partnership is dependent on the ability of people possessing diverse perspectives to meet and actively participate. However, cultural differences also can interfere with the group process. Because culture influences our behavior and the way we communicate, members should understand and be sensitive to the influence another member’s cultural perspective may have on the group.

Partnerships often decide to offer members training in **cultural competence**. The National Center for Cultural Competence suggests the following tips to help achieve cultural competence among group members:

- Have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally.
- Have the capacity to value diversity; conduct self-assessment; manage the dynamics of difference; acquire and institutionalize cultural knowledge; adapt to diversity and the cultural contexts of the communities they serve.
- Incorporate the above in all aspects of policy making, administration, practice, service, delivery and involve systematically consumers, key stakeholders and communities (Goode, 1999/2003).



It is not easy to resolve unequal power within multicultural groups. The following recommendations also may be helpful:

- Acknowledge diversity within racial and ethnic groups and be open to learning about different cultures.
- Use the research process and its outcomes to mobilize and advocate for change to reduce disparities and improve relations.
- Listen, listen and listen. Pay close attention to the concerns of diverse community groups.
- Build true multicultural working relationships. (Chavez, Duran, Baker, Avila & Wallerstein, 2003, p.92-93).

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**“To achieve cultural competence. . .group members [should]. . .value diversity. . . and adapt to the cultural contexts of the communities they serve.”**

**National Center for Cultural Competence**

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## CASE STORY

### Embracing Diversity within the GENE Project

The GENE Project was a multicultural collaboration that embraced the principles of CBPR and cultural and linguistic competence. Members of the national partnership came from diverse geographic and racial/ethnic backgrounds. Efforts were made to partner with community organizations that represented the key stakeholders in the Hispanic/Latino and African American communities. Project staff, consultants and organizational representatives also were selected carefully so that community members could identify with them more easily. Community meetings were conducted in a culturally and linguistically appropriate manner. For example, a translator was included in the WH/I GENE Coalition’s budget so that members who were not bilingual could still participate in the discussion. Materials developed for and by the WH/I Coalition were provided in both English and Spanish.

Though the road to partnership was also made challenging by the diversity in personalities, the journey proved to be worthwhile. GENE Project national and community partners learned from each others’ experiences. African American and Hispanic/Latino communities are not homogeneous. Diversity can exist within a given racial or ethnic group due to socioe-

conomic status, levels of education, acculturation and assimilation. Members of each GENE Project community developed a greater understanding of how other African Americans and Hispanics/Latinos addressed social, health and political issues such as genetics. They learned additional methods of how to reach and teach their respective communities.

As a result of the GENE Project collaboration, each community conducted a successful community needs assessment to gain more information on the knowledge and attitudes of African Americans and Hispanics/Latinos towards genetics education. They learned about the most effective strategies for communicating health messages to their constituents. They also gained insight into the different genetics topics that each population was most interested in learning about. The diversity of the GENE Project coalition was its strength. Because of the information that the WH/I GENE Coalition and MI GENE Demonstration Project collected, people had the information needed to create more culturally and linguistically appropriate genetics education materials and resources for the African American and Hispanic/Latino communities.

## Sustainability

Sustainability refers to how to keep partnerships going. Most people think money sustains a group. Funding is important, but it is not the only way to maintain partnerships. **Capacity-building**, in the form of training and information sharing, can enhance the contribution of community members. Training and information sharing helps to increase community members' knowledge and build skills that will remain within the community long after the project ends. However, capacity-building requires additional time and resources from the lead agency.

Another way to maintain partnerships is to recruit new members. These individuals bring fresh energy and ideas to the group. They bring an opportunity for new leadership and a chance to reexamine and update the priorities of the group.

Still another way to sustain a partnership is to celebrate its successes. Take note of your achievements and celebrate your accomplishments and strengths (Cohen et al., 2002, p. 161-178).

## CASE STORY

### Sustaining GENE Project Community Efforts

#### Michigan GENE Demonstration Project

When the three years of funding ended, the Michigan Community Advisory Board (CAB) was not successful in obtaining another opportunity to work with the March of Dimes and its national partners. Many changes within the structure of the University as well as some of the CBOs prohibited the CAB from continuing its work together. However, some of the partners continue to share information and engage community members in learning and sharing information about genetics, utilizing tools and information gained from this experience. Community members who participated in the MI GENE Demonstration Project's dialogue groups and town hall meetings continue to be involved in genetics-related activities and share information about the topic with others in their communities. They have also been invited to participate in a regional forum to discuss genomics and genetics information. The Executive Director of the Flint-based CBO Faith Access to Community Economic Development (FACED) was invited to the March of Dimes national office to give a talk on how to reach the African American community using participatory approaches. FACED also serves as a member of the national advisory network for a new March of Dimes project focused on the development of culturally sensitive genetics education materials.

#### Washington Heights/Inwood GENE Coalition

Over the course of the project, WH/I GENE Coalition members benefited from an increase in knowledge about genetics and its relation to health. The project provided temporary job and learning opportunities for several community residents, which created valuable and transferable skills that could be used in the future. WH/I GENE Coalition members and staff were trained in several research areas. For example, they learned how to develop survey instruments, conduct survey interviews, moderate focus groups, enter and interpret data, disseminate results and evaluate their project. The March of Dimes also provided connections to other organizations and letters of support that would assist the coalition in obtaining new funds to sustain project activities. Through the GENE Project, the WH/I GENE Coalition and the Dominican Women's Development Center (DWDC) increased their visibility in the community and, as a result, the local university hospital, Columbia University Medical Center, invited the coalition to partake in other community-based initiatives. DWDC was also successful in obtaining a new competitive grant with the March of Dimes to carry out their community action plan, which was based on the results of their GENE Project needs assessment. The coalition is currently developing a bilingual training curriculum for community health workers on the subject of human genetics so that they can educate community residents.

## Finding Solutions

As you build and try to maintain your partnership, you will continue to encounter new challenges that require creative and thoughtful solutions. The table below summarizes some strategies you might use to address challenges that arise in building and sustaining a partnership, many of which have been described throughout this toolkit.

### Overcoming Key Challenges of Community-Based Participatory Partnerships

- Take time to learn about the people, politics and dynamics of the community before you approach members.
- Work with people who share a common commitment to solving the community problem.
- Allow enough time to build and nurture relationships with your partners.
- Understand group process: how groups develop, mature and work together on common problems and then end or separate once the work has been completed.
- Develop rules to guide the group's work.
- Support leadership development and capacity-building among group members.
- Understand how to run meetings, engage in group negotiations and foster decision-making.
- Set up an effective communication system.
- Be clear and open about how much money and staff support the project has.
- Create a flexible timeline for the program.

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## Regularly Evaluate Your Partnership

Assess your partnership on a regular basis. Ask the following questions: Does it still meet our objectives? Are new members needed? Do we need to change our structure? Evaluating your partnership is an ongoing process that can begin as early as the first community meeting. One way to evaluate your partnership's progress and group process is to collect information from meeting evaluation forms. Make sure to include open-ended questions on the forms. Review the feedback and respond to group members as needed.

Sometimes partnership members agree early on to dissolve the group as soon as the major goals have been met or because the partnership's original funding stream has come to an end. At other times, members may decide that for other reasons it is the right time for the group to end.

When a partnership ends, it is critical that something of value is left behind for the community. For example, you might have trained community members, and that skill base will be the partnership's legacy.

Or the partnership may have facilitated greater access to essential services or written a proposal to obtain additional funding for new activities.

Though the partnership may end, it does not mean that your relationships must also end. Ask yourself the following questions:

- Are you or your organization more widely accepted in the community?
- Are you invited to more community events?
- Are you seen as a new resource in the community for your area of expertise?
- Have you created friendships with individuals in the community that will last beyond the project and can be called upon for future initiatives?
- Were your efforts successful in building or rebuilding trust?

If you are able to answer yes to any or all of these questions, the advantages of having participated in a partnership and benefits to both the community and your organization will endure beyond the life of the group. Use the table below to evaluate whether your partnership is or has been successful.

#### **Selected Characteristics of a Successful Community-Based Participatory Partnership**

- Shares a vision.
  - Has strong and effective leaders.
  - Has a clear set of group rules.
  - Has a diversified membership.
  - Seeks meaningful community participation at the beginning and for the duration of the project.
  - Shares governance and ownership among members.
  - Has multiple sources of funding to sustain community partnerships.
  - Builds community capacity by providing technical support, training and job opportunities.
  - Fosters a spirit of cooperation, trust and honesty.
  - Shows group commitment and cohesiveness.
  - Has active participation and interaction between and among members.
  - Engages in actions to solve important community problems.
  - Facilitates individual and community empowerment.
-

## Summary

In recent years, funders, organizations and communities have recognized the importance of forming community-based participatory partnerships to improve the public's health. But, building and sustaining a community-based participatory partnership can be challenging. It requires careful planning, a commitment of time and resources, effective leadership and the active, equitable participation of all the members.

This toolkit has given you basic information to build new relationships with diverse communities so that you can work together to address an important community need or problem. Additional references and resources are available in Appendix C to assist you as you continue to develop your partnership. However, there is not one “recipe” for working with community members. You may encounter some challenges not covered in this guide. Each partnership is unique, and is influenced by the history, culture, politics and geographic location of the community. Continue to listen, observe and be flexible as you deal with changing group dynamics. Evaluate your partnership on a regular basis to ensure that it is meeting its intended purpose. You may need to be open to change so that the group can take the next step toward achieving its common mission and vision.



Representatives of the MI GENE Project. Standing (left to right): Rosalyn Y. Beene, Amin Mugeru. Sitting (left to right): Othelia Pryor, E. Yvonne Lewis.



Representatives of the WH/I GENE Project Coalition. Standing (left to right): Claudia de la Cruz, Aida Giachello, Jesus Sanchez. Sitting (left to right): Rosita Romero, Maria Zoquier-Estevez.



## APPENDIX A: TERMS TO KNOW

**Advisory Committees** – groups of individuals who provide suggestions and technical assistance to organizations and programs.

**Bylaws** – formal document that states the mission, purpose, goals and objectives of a corporation. Lays out the roles and responsibilities of members, defines the group’s organizational structure and establishes meeting rules.

**Catalyst** – stimulates discussion with a longer-term strategy in mind.

**Chair** – acts as spokesperson for the coalition; may sign letters, testify in court, etc.

**Coalitions** – organizations that are made up of groups and individuals working together for a common purpose.

**Commissions** – citizens appointed by official bodies to review or develop policies.

**Community** – a group of people who have similar characteristics or a shared identity.

**Community Advisory Board (CAB)** – a group of leaders from the community who guide the development of the partnership and program.

**Community-Based Participatory Partnership (CBPP)** – a collaborative body of individuals and organizations working together on a common goal or issue of importance to the community. Consists of a mutually beneficial relationship where all parties have shared responsibilities, privileges and power.

**Community-Based Participatory Research (CBPR)** – method of engaging members of a community in the conduct of research. Researchers and community members work side by side to identify a problem in need of investigation and to develop and implement a research plan to learn more about the problem. Results of the research are later presented to the community at large, and a plan of action is developed to address the problem.

**Conduit** – acts as the lead agency in providing funding for local collaborative projects.

**Consortia and Alliances** – semi-official, membership organizations. They typically have broad policy-oriented goals and may span large geographic areas. They usually consist of organizations and coalitions rather than individuals.

**Contract Agreement** – legal document that details program deliverables and financial arrangements.

**Convener** – leads a highly visible public discussion of community issues in order to highlight a common understanding of the issues.

**Cultural Competency** – set of knowledge, skills and attitudes that allows you and your organization to work effectively with diverse racial, ethnic, religious, low income and other social groups.

**Cultural Humility** – a “lifelong commitment to self-evaluation and self-critique” to redress power imbalances and develop and sustain mutually respectful partnerships with communities. Achieving cultural humility involves a willingness to acknowledge forms of inequality, such as institutionalized racism, and an openness to learning how to work effectively across cultures and diverse populations.

**Cultural Sensitivity** – understanding the needs and emotions of your own culture and the culture of others.

**Facilitator** – can run a meeting, fosters group discussions and resolves disagreements in the group. Facilitators encourage trust and create a safe environment that enables group members to participate and share ideas.

**Funder** – provides public and private funds to support the project; may choose to be involved in the design and planning of the project.

**Gatekeepers** – individuals who know the community, its issues and its players. May be well-respected, well-known leaders who influence community issues.

**Goals** – “action-oriented” and defined as the ideal outcomes the organization hopes to achieve. They are expressed as general statements that say what you want to accomplish, the type and amount of change you want to take place, and how long it should take to make the change.



**Individual Member** – does not represent a specific organization within the coalition; often joins the coalition for personal or professional interest in the issue.

**Key Informants** – individuals who have spent enough time in the community to have gained special knowledge about the community. They are “thoughtful observers and informal historians” who can articulate important issues of culture, key groups and relationships and perceived barriers.

**Key Informant Interviews** – face-to-face or telephone interviews with gatekeepers to learn about the community and brainstorm possible partners

**Linguistic Competence** – the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences.

**Memorandum of Understanding** – a formal document that lays out scope of the work and nature of the relationship.

**Mission** – describes what the organization is going to do and why it’s going to do it.

**Networks** – loose-knit groups formed primarily for the purpose of resource and information sharing.

**Objectives** – specific strategies and tasks that will be used to reach one’s goals.

**Partnerships Guidelines** – document that defines the partnership, outlines partnership principles to guide the group’s process, clarifies goals and responsibilities, and expectations of the partnership members.

**Principal Investigator (PI)** – the individual responsible for leading and directing a research grant, cooperative agreement, training or public service project, contract or other sponsored project.

**Stakeholders** – individuals or groups affected most by the issue you are addressing.

**Steering Committee** – group of leaders who take the initiative to move the project forward.

**Task Forces** – individuals who come together to accomplish a specific series of activities, often at the request of an overseeing body.

**Underserved or Under-Represented** – people who face ethno-cultural and other barriers to care, including ethnic/racial minorities, recent immigrants and refugees.

**Vision** – communicates what your organization believes are the ideal conditions for your community; how things would look if the problem were carefully addressed.



## APPENDIX B: TOOLS

- B1** Sample Coalition Recruitment Flyer (English and Spanish)
- B2** Sample Coalition Membership Form (English and Spanish)
- B3** Sample Coalition Meeting Evaluation Form (English and Spanish)
- B4** Meeting Minutes Template
- B5** Sample Decision-making Framework



## WASHINGTON HEIGHTS / INWOOD GENE PROJECT COALITION

The Genetics Education Needs Evaluation (GENE) Project is a five-year venture to investigate and improve access to genetics information. Launched in June 2000, it is managed by the March of Dimes under a cooperative agreement with the Maternal and Child Health Bureau of the Health Resources and Services Administration. The long-range vision of the GENE Project is to create a network in Washington Heights and Inwood. This network will develop culturally appropriate human genetic information that will assist individuals and groups in getting information and making informed choices about health.

**Next Meeting: Tuesday, April 29, 2003**

**1-3 PM**

**Alianza Dominicana  
2410 Amsterdam Ave. (and 180<sup>th</sup> St.)  
3<sup>rd</sup> Floor Conference Room**

**Lunch will be provided.**

**You should come to this meeting if:**

**You work with children**

**You have a business in Washington Heights/Inwood**

**You run a community based organization**

**You work with families with inherited medical conditions (i.e. diabetes)**

**Visit [http://www.groups.yahoo.com/group/gene\\_coalition/](http://www.groups.yahoo.com/group/gene_coalition/) for more information.**

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### **Washington Heights/Inwood GENE Project Coalition Members**

**HRSA - March of Dimes - Community Board 12 - CUNY Dominican Studies Institute  
Dominican Women's Development Center - Family Voices - Ft. George Community Enrichment Center, Inc. - Genetic Alliance  
Northern Manhattan Perinatal Partnership, Inc. - NY Presbyterian Hospital - YMA/YWHA of Washington Heights/Inwood**



**WASHINGTON HEIGHTS / INWOOD GENE PROJECT COALITION**

**RESPONSE FORM**

Name \_\_\_\_\_

Organization \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Telephone # \_\_\_\_\_

Fax # \_\_\_\_\_

E-Mail \_\_\_\_\_

**Please check one:**

**YES. I am attending this meeting.**

**NO. I am not able to attend this meeting but am interested in the GENE Project and would like more information.**

**NO. I am not able to attend this meeting but am sending the following representative from my organization:**

Name: \_\_\_\_\_ Title: \_\_\_\_\_

**NO. Thank you for your invitation, but I am not available or interested in the GENE Project at this time. Please remove me from your mailing list.**

**Please fax or email your response to:**

**Maria Zoquier**

**Dominican Women's Development Center/ Project Coordinator**

**Fax: 212-994-6065**

**Email: mzoquier@dwdc.org**



**LA COALICION DEL PROYECTO DEL GENE  
DE WASHINGTON HEIGHTS / INWOOD**

El Proyecto de Evaluación de Educación Sobre la Genética conocido en inglés con las ciclas GENE, es un proyecto de demostración de cinco años que investiga el como aumentar el acceso a información genética al público en general. El Proyecto se inició en Junio del 2000, y es administrado por la oficina nacional del March of Dimes bajo un acuerdo cooperativo del Negociado Materno-Infantil de la administración de Servicios y Recursos Sobre Salud del gobierno federal. La visión a largo plazo del Proyecto GENE es crear una red de individuos y organizaciones en Washington Heights y Inwood. Esta red desarrollará información culturalmente apropiada sobre la genética humana que asistirá a individuos y a grupos a hacer las decisiones necesarias sobre la salud.

Próxima Reunión: Martes, 29 de abril del 2003

1-3 PM

Alianza Dominicana  
2410 de la Avenida Amsterdam (y calle 180)  
Tercer Piso

Se servirá Almuerzo.

Usted debe de asistir a esta reunión si:

Usted trabaja con niños

Usted tiene un negocio en Washington Heights/Inwood

Usted dirige o trabaja en una organización comunitaria

Usted y su familia tiene o trabaja con familias que tienen condiciones médicas hereditarias (i.e. diabetes)

Visite [http://www.groups.yahoo.com/group/gene\\_coalition/](http://www.groups.yahoo.com/group/gene_coalition/) para más información.

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Miembros de la Coalición del Proyecto Gene de Washington Heights/Inwood

HRSA March of Dimes Community Board 12 CUNY Dominican Studies Institute

Dominican Women's Development Center Family Voices Ft. George Community Enrichment Center, Inc. Genetic Alliance Northern Manhattan Perinatal Partnership, Inc. NY Presbyterian Hospital YM&YWILA of Washington Heights/Inwood



**LA COALICION DEL PROYECTO DEL GENE  
DE WASHINGTON HEIGHTS / INWOOD**

**HOJA DE RESPUESTA**

Nombre \_\_\_\_\_

Organización \_\_\_\_\_

Dirección \_\_\_\_\_

# de Teléfono \_\_\_\_\_

# de Fax \_\_\_\_\_

Correo electrónico/E-Mail \_\_\_\_\_

Favor de Marcar una:

**SÍ, voy a participar en la reunión de la coalición.**

**NO puede participar en la reunión pero estoy interesado(a) en el Proyecto del GENE y deseo más información.**

**NO puedo participar en la reunión pero estoy enviando el siguiente representante de mi organización:**

Nombre \_\_\_\_\_ Título: \_\_\_\_\_

**NO. Gracias por su invitación, pero no estoy disponible ni interesado(a) en estos momentos en el Proyecto del GENE. Favor de sacar mi nombre de su lista.**

**Favor de enviar su respuesta por fax o por correo electrónico a:  
Maria Zoquier  
Dominican Women's Development Center / Coordinador de Proyecto  
Fax: 212-994-6065  
Email: mzoquier@dwdc.org**

## The Washington Heights-Inwood Genetic Education and Evaluation (GENE) Project

### MEMBERSHIP APPLICATION

We invite YOU to become a member of WII GENE Project—a community-wide coalition of individuals and organizations engaging in community training, awareness, education, and a community needs and assets assessment, regarding issues of genetics. Our ultimate goal is to create a network in Washington Heights-Inwood that will increase and improve access to culturally and linguistically-appropriate genetics information and services.

If you are interested in joining our group, please fill out the following information:

1. Name: \_\_\_\_\_  
                                    First Name                                      Initial                                      Last Name
  
2. Address: \_\_\_\_\_  
                                    Number/Name of Street or Avenue                                      Apt. #  
  
\_\_\_\_\_  
                                    City, State, Zip Code
  
3. Name of Organization: \_\_\_\_\_
  
4. Title: \_\_\_\_\_
  
5. Phone: \_\_\_\_\_                                      6. Fax: \_\_\_\_\_
  
7. E-mail: \_\_\_\_\_
  
8. Would you like to be added to the WII Coalition listserv? (Check one.)    Yes                                      No
  
9. How would you prefer to receive updates? (Check all that apply.)    Email                                      Regular Mail                                      Fax                                      Phone
  
10. With what racial or ethnic group or country do you identify with? \_\_\_\_\_
  
11. What type of membership do you represent? (Check one.)    Individual                                      Organization
  
12. Which committee(s) would you like to participate in? (Check all that apply.)  
Community Awareness \_\_\_\_\_ Education/Training \_\_\_\_\_ Community Needs and Assets Assessment \_\_\_\_\_
  
13. Signature: \_\_\_\_\_                                      Date: \_\_\_\_\_

Please distribute this application to fellow community residents and organizations in your area that may be interested.

Please return this form during the coalition meeting or mail or fax to:

WII/GENE COALITION  
c/o Dominican Women's Development Center  
519 189<sup>th</sup> St.  
New York, NY 10040  
Fax: (212) 994-6065

For more information, please visit our listserv web page at: [http://www.groups.yahoo.com/group/genec\\_coalition](http://www.groups.yahoo.com/group/genec_coalition).





WHI GENE Project Coalition  
*Coalición del Proyecto GENE del WH/I*

MEETING EVALUATION FEEDBACK FORM  
*HOJA DE EVALUACION DE REUNION*

Do not write your name on this form. *Favor de no Escribir su nombre en esta hoja.*

Please take a couple of minutes at the end of the meeting to complete this form. The feedback will help us improve the quality and friendliness of the meetings. *Favor de tomar unos minutos a finalizar la reunión para completar esta hoja. Sus comentarios nos ayudarán a mejorar la calidad y el ambiente de las reuniones.*

Date of Meeting:

*Día de Reunión:*

Location:

*Lugar:*

Please circle your response. (T=True, F=False, DK=Don't Know)

*Favor de marcar sus respuestas. (C=Cierto, F=Falso, NS=No Sé)*

|                  |  |
|------------------|--|
| T F DK<br>C F NS | I was notified of this meeting with sufficient notice.<br><i>Fui notificado(a) a esta reunión con suficiente notificación.</i> |
| T F DK<br>C F NS | The meeting started and ended on time.<br><i>La reunión comenzó y terminó a tiempo.</i>  |

| How would you rate each of the following:<br><i>Como evaluaría Usted los siguientes detalles:</i><br>(Please circle your response. <i>Favor de hacer un círculo a su respuesta.</i> ) | Poor<br><i>Pobre</i> | Fair (regular)<br><i>Regular</i> | Good<br><i>Bueno</i> | Excellent<br><i>Excelente</i> |
|---|----------------------|----------------------------------|----------------------|-------------------------------|
| The agenda (clear?)<br><i>La agenda (Estuvo clara?)</i>   | 1                    | 2                                | 3                    | 4                             |
| The objectives (appropriate)<br><i>Los objetivos (apropiados?)</i>  | 1                    | 2                                | 3                    | 4                             |
| The location of the meeting<br><i>La locación de la reunión</i>   | 1                    | 2                                | 3                    | 4                             |
| Quality of the facilitators/presenters<br><i>Calidad de los facilitadores/presentadores</i>   | 1                    | 2                                | 3                    | 4                             |
| Information shared in this meeting<br><i>Información compartida en la reunión</i>   | 1                    | 2                                | 3                    | 4                             |
| The way decisions were made<br><i>La forma en que las decisiones fueron tomadas</i>   | 1                    | 2                                | 3                    | 4                             |

**APPENDIX B3 – Sample Coalition Meeting Evaluation Form, Page 2 (English and Spanish)**

|   |   |   |   |   |
|---|---|---|---|---|
| The handouts (appropriate, useful)<br><i>Las hojas de información distribuidas (Apropiadas, utiles?)</i>  | 1 | 2 | 3 | 4 |
| Opportunities for participation and sharing<br><i>Oportunidades para participación y para compartir</i>   | 1 | 2 | 3 | 4 |
| The action plan or strategies/developed developed<br><i>El Plan de Acción o estrategias desarrolladas</i> | 1 | 2 | 3 | 4 |
| Assignment or follow-up tasks<br><i>Asignaciones o seguimiento de tareas.</i>                             | 1 | 2 | 3 | 4 |

(Write in English or Spanish. *Escriba en Inglés o Español.*)

Was this meeting worth your time? *En término de su tiempo, valió la pena esta reunión?*

What did you learn today? *Que aprendió Usted hoy?*

What went well in this meeting? *Qué cosas buenas ocurrieron en esta reunión?*

What could have gone better? *Qué cosas pueden mejorarse?*

**THANK YOU FOR YOUR COOPERATION!  
GRACIAS POR SU COOPERACION!**



## APPENDIX B5 – Sample Decision-Making Framework

### **DECISION-MAKING FRAMEWORK**

A vast array of decisions will have to be made throughout the course of the coalition. It is impossible to anticipate all of them, but it is helpful to have some idea of how certain types of decisions will be handled. For each of the following types of decisions indicate with a ✓ mark where you think the principal decision making responsibility should be.

|  | Principal Investigators | Steering Committee | Project Coordinator | Task Force (committee) Members | General Coalition Membership |
|--|-------------------------|--------------------|---------------------|--------------------------------|------------------------------|
| <b>Membership</b>  |                         |                    |                     |                                |                              |
| Recruit coalition members  |                         |                    |                     |                                |                              |
| Provide orientation activities.  |                         |                    |                     |                                |                              |
| Assure a diverse membership.   |                         |                    |                     |                                |                              |
| Establish clear roles & responsibilities for coalition members.  |                         |                    |                     |                                |                              |
| Keep members informed through on-going communication.  |                         |                    |                     |                                |                              |
| Ensure active participation in coalition activities  |                         |                    |                     |                                |                              |
| <b>Coalition Visions, Goals &amp; Objectives</b>   |                         |                    |                     |                                |                              |
| Establish & review vision, goals & objectives.   |                         |                    |                     |                                |                              |
| Communicate goals & objectives to non- members.  |                         |                    |                     |                                |                              |
| <b>Community Mobilization &amp; Outreach</b>   |                         |                    |                     |                                |                              |
| Focus public attention on issues related to genetic risk factors.  |                         |                    |                     |                                |                              |
| Give presentations.  |                         |                    |                     |                                |                              |
| Work on the newsletter   |                         |                    |                     |                                |                              |
| Talk to the media.   |                         |                    |                     |                                |                              |
| Meet with other community organizations & local leaders.   |                         |                    |                     |                                |                              |
| Represent the coalition.   |                         |                    |                     |                                |                              |
| <b>Coalition Operations</b>  |                         |                    |                     |                                |                              |
| Ensure partner agreements are maintained   |                         |                    |                     |                                |                              |
| Hold members accountable for their commitments.  |                         |                    |                     |                                |                              |
| Scheduling Decisions:  |                         |                    |                     |                                |                              |
| Coalition meetings   |                         |                    |                     |                                |                              |
| Committee meetings   |                         |                    |                     |                                |                              |
| Core group (steering committee) meetings   |                         |                    |                     |                                |                              |
| Personnel issues (underperforming staff, etc )   |                         |                    |                     |                                |                              |
| Staff hiring issues  |                         |                    |                     |                                |                              |
| Major equipment purchases  |                         |                    |                     |                                |                              |
| <b>Conflict Resolution</b>   |                         |                    |                     |                                |                              |
| Resolve differences of opinion on the role/scope of the core group (steering committee)                        |                         |                    |                     |                                |                              |
| How to handle "public relations" problems (misunderstandings in the community regarding the coalition's work). |                         |                    |                     |                                |                              |
| How to handle replacing members of the core group who leave  |                         |                    |                     |                                |                              |
| How/when to expand the core group  |                         |                    |                     |                                |                              |
| <b>Sustainability</b>  |                         |                    |                     |                                |                              |
| How and when to seek additional funding for coalition work   |                         |                    |                     |                                |                              |
| Grant reports, activity write-ups etc.   |                         |                    |                     |                                |                              |
| <b>Planning &amp; Evaluation</b>   |                         |                    |                     |                                |                              |
| Address perceived gaps in interventions & other activities   |                         |                    |                     |                                |                              |
| How to handle recruitment of participants to training programs   |                         |                    |                     |                                |                              |
| Curriculum decisions for training programs   |                         |                    |                     |                                |                              |
| Evaluation design & planning decisions   |                         |                    |                     |                                |                              |
| Scope of evaluation activities   |                         |                    |                     |                                |                              |
| Resolve disagreements on evaluation materials & questionnaires   |                         |                    |                     |                                |                              |
| Focus of networking efforts  |                         |                    |                     |                                |                              |
| Overall networking strategy  |                         |                    |                     |                                |                              |



## APPENDIX C: REFERENCES AND ADDITIONAL RESOURCES

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## **ADDITIONAL RESOURCES**

### **Community-Campus Partnerships for Health**

A nonprofit organization that promotes health through partnerships between communities and higher educational institutions, service-learning, community-based participatory research and broad-based coalitions.

<http://depts.washington.edu/ccph>

### **Community Toolbox**

Online resource of practical skill-building information to support your work in community health and development.

<http://ctb.ku.edu>

### **Dominican Women's Development Center**

A not-for-profit organization created to empower Dominican/Latina women and their families who reside in Washington Heights, and organize women to actively participate in the elimination of gender inequality and promotion of social justice.

[www.dwdc.org](http://www.dwdc.org)

### **Faith Access to Community Economic Development**

A not-for-profit organization that provides services to meet the comprehensive health needs – physical, mental and spiritual – of low-income residents of Flint/Genesee County, Michigan.

[www.facedcorp.org](http://www.facedcorp.org)

### **Family Voices**

A national grassroots network of families and friends that advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs. Promotes inclusion of families as decision makers at all levels of health care and supports essential partnerships between families and professionals.

[www.familyvoices.com](http://www.familyvoices.com)

### **Genetic Alliance**

A coalition of more than 600 advocacy organizations dedicated to improving the life of everyone living with genetic conditions and building capacity in all communities.

[www.geneticalliance.org](http://www.geneticalliance.org)

## **March of Dimes Foundation**

National voluntary health agency whose primary mission is to improve the health of babies by preventing birth defects, premature birth and infant mortality through programs of research, community services, education and advocacy.

[www.marchofdimes.com](http://www.marchofdimes.com) or [www.nacersano.org](http://www.nacersano.org)

## **National Center for Cultural Competency**

Provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations.

[www11.georgetown.edu/research/gucchd/nccc/](http://www11.georgetown.edu/research/gucchd/nccc/)

## **U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA)**

Primary Federal agency that provides national leadership, program resources and services needed to improve access to culturally competent, quality health care.

[www.hrsa.gov](http://www.hrsa.gov)

## **U.S. Department of Health and Human Services, Maternal and Child Health Bureau (MCHB)**

Provides national leadership and works in partnership with states, communities, public-private partners, and families to strengthen the maternal and child health (MCH) infrastructure, assure the availability and use of medical homes, and build knowledge and human resources in order to assure continued improvement in the health, safety and well-being of the maternal and child health population.

[www.mchb.hrsa.gov](http://www.mchb.hrsa.gov)







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