

# **Community Research Collaboration**

Memorandum of Understanding (MOU)

CBCRP does not require, but strongly encourages, CRC teams to develop MOU's.

Attached is a section from a curriculum on community-based participatory research that can be used by teams to develop the organizational structure of their partnership (1). The entire curriculum can be found at <a href="http://www.cbprcurriculum.info/">http://www.cbprcurriculum.info/</a>.

Also attached are sample copies of MOU's that have been used by other community-researcher collaborations. Having a written document which records the agreements made by the partnership is an invaluable way to minimize disagreements and can be helpful when bringing new individuals into an established partnership.

The final document is a copy of the board resolution that is required in the CRC application process to document that the community organization's board of directors is aware of the agreements made by the co-PI's with regards to: ownership of data, handling disagreements, recipient of grant award, plans for broader community involvement, and plans for dissemination of findings.

1. Palermo A, McGranaghan R and Travers, R. Unit 3: Developing a CBPR Partnership – Creating the "Glue." In: The Examining Community-Institutional Partnerships for Prevention Research Group. Developing and Sustaining Community-Based Participatory Research Partnerships: Skills-Building Curriculum, 2006. www.cbprcurriculum.info.

# Unit 3 Section 3.3: Creating a Mission Statement and By-Laws

# Organizational structure of the partnership

Throughout the process of establishing a CBPR partnership, it is equally important to devote time and resources to developing an effective organizational structure that will provide support to the partnership.

Given that each partner organization has its own missions, goals and objectives, community-institutional partnerships for prevention research need to engage in a process of creating a common vision and selecting and prioritizing mutually defined issues, goals and objectives that reflect the multiple agendas that partners bring to the table.

Shared vision is vital in order for partnerships to succeed because it provides focus and energy. Without a vision, separate self-interests can override partnership interests. With a common vision, partnerships apply collective power and subordinate separate self-interests to the larger purpose. Without a shared vision, there is no partnership; rather, it is merely a coalition or information-sharing group.

By developing a mission statement or set of by-laws together, every organizational partner will feel that they had a role in developing and articulating this shared vision. In addition to the overall mission and vision of the partnership, the mission statement or by-laws should acknowledge the values which the partnership seeks to uphold, including:

- Equal participation by all partners in all aspects of the partnership's activities
- · Recognition that all partners have expertise that they bring to the partnership
- Recognition that community-based research is a collaborative process that is mutually beneficial to all partners involved
- Recognition that health is more than the absence of disease and that to ensure good health, individual, political, economic, and environmental risk factors in the community have to be addressed

A mission statement states the purpose of the partnership, while by-laws are the official rules and regulations which govern a partnership. In the context of CBPR partnerships, whether a partnership decides to articulate their shared vision and values through its mission statement or by-laws has little consequence; this decision is more of a question of style.

# Exercise 3.3.1: Creating a "Shared Vision" for the Partnership

This exercise can take place in one large group or several small groups.

Participants take 15 minutes to generate a list of key words and phrases that characterize a common vision for their partnership(s), based on the issue(s) they are addressing or hope to address. Small groups report out what they have listed and the large group identifies common themes.

# Example 3.3.3: CBPR Partnership Operating Procedures and By-laws

Harlem Community & Academic Partnership Operating Procedures and By-Laws

### (August 2004)

This document outlines the guidelines and operating procedures of the Harlem Community & Academic Partnership to conduct regular business, designing and implementing projects, and disseminating information related HCAP activities.

- 1. Name: The official name shall be Harlem Community & Academic Partnership.
- 2. Location: The Harlem Community & Academic Partnership (HCAP) is housed at the Center for Urban Epidemiologic Studies (CUES) at the New York Academy of Medicine (NYAM). The HCAP primarily concentrates its activity on the Harlem community which is defined as the neighborhoods of East and Central Harlem. The HCAP will also expand its focus to other New York City communities for specified projects.
- **3. HCAP Structure:** The HCAP is governed by committee comprised of community and academic partners. The committee is led by a chairperson and a vice-chairperson when chairperson is not available.

### 4. HCAP Meetings:

- 4.1 The HCAP will meet monthly, on the second Tuesday of every month. Minutes are available and distributed monthly.
- 4.2 Priority in any HCAP discussion will be given to emergent issues that affect the community and/or to HCAP members who have been most involved with a particular topic to be addressed in the presentation.
- 4.3 The HCAP will make a reasonable effort to reach consensus agreement on all issues. In the absence of consensus, a majority of all votes cast will determine action taken by the HCAP membership.

# 5. HCAP Membership and Voting:

- 5.1 The HCAP will consist of representatives of CUES, local community residents, local community-based organizations, public health agencies, and educational institutions.
- 5.2 A HCAP member may be represented by either an individual or an organization/institution. For procedural purposes, individual representatives seeking membership must attend two out of three meetings within a 3 month period. Organizations seeking membership must attend three consecutive meetings by having the same organizational representative attend each meeting to establish membership. Once membership has been established, the organization may send a proxy representative thereafter. Any individual who meets these requirements and completes a membership application will be considered a member. HCAP members maintain the right to vote once membership status has been achieved.
- 5.3 Multiple representatives from one agency, organization, or institution will assign one person to serve as the voting representative for the October-September meeting cycle. The formal voting members of the

HCAP will be all persons who meet the criteria in 5.2. Each HCAP member agency, organization, or institution will have one vote. Each individual community resident will have one vote. The HCAP Chairs (s) will vote only if there is a tie.

- 5.4 Voting HCAP membership will then consist of all representatives classified as HCAP voting members in 5.3. Fifty per cent plus 1 of HCAP members present shall constitute quorum. All voting HCAP members have one vote for the purposes of formal procedural issues.
- 5.5 To ensure that the HCAP reflects the views of the community and its community-based organizations, at any given time a majority of HCAP members with the right to vote must represent community-based organizations or are community residents. New members will be admitted to maintain this balance.
- 5.6 Voting HCAP members will be compromised of community-based experts or experts on health issues that are of a burden to the Harlem community and other geographical areas of interest to the HCAP.

# 6. HHCAP Voting Member Elections and Term Limits:

- 6.1 A HCAP Chair(s) will be elected by a majority vote from the current voting HCAP members on a yearly basis at the October HCAP meeting.
- 6.2 There are no term limits for any of the other HCAP voting or non-voting positions.

## 7. HCAP Chair:

7.1 The HCAP Chair(s) is responsible for the orderly conduct of HCAP meetings, designating a CUES staff person to record minutes, setting the HCAP agenda, and ensuring active participation of HCAP members in all aspects of HCAP activity.

# 8. HCAP Activities:

- 8.1 The HCAP shall endeavor to fulfill its mission through research, and intervention in Harlem and other geographical areas of interest.
- 8.2 HCAP members are encouraged to present project proposals or ideas to the HCAP; the HCAP shall then decide on which projects to take on as HCAP projects.
- 8.3 An Intervention Work Group (IWG) will be formed to monitor each project undertaken by the HCAP; each project will be overseen by its own IWG, which will report to the HCAP on a regular basis.
- 8.4 A CUES Project Manager will be assigned to HCAP to work closely with the HCAP Chair and CUES Investigators to act as a liaison between HCAP members and CUES investigators.
- 8.5 To the extent feasible, there should always be at least one voting HCAP member and one CUES member involved in all HCAP projects. These members should be involved in all stages of the project including

conceptualization, design, implementation, analysis and dissemination of results. CUES Investigators will work closely with the HCAP Chair and voting members on project proposals and writing of research grants and publications for select projects.

- 8.6 Members of the IWG should report back to the HCAP on project progress and results at regular pre-determined intervals during HCAP meetings.
- 8.7 To the extent feasible, abstracts and manuscripts arising from HCAP or HCAP IWG work that are intended for academic publication should be shared with the HCAP for comment/feedback before submission.
- 8.8 HCAP members and CUES staff who have worked on particular projects will be co-authors on publications. In the event of limited number of authors limited by a particular publication, priority will be given to persons who have been most involved with a particular project.
- 8.9 The HCAP will be acknowledged in every article.

### 9. HCAP Vice-Chair:

9.1 The HCAP Vice-Chair serves as the secondary representative of the HCAP and to support the HCAP Chair in organizing the quality work efforts and the research and intervention goals of the HCAP.

# 10. Changes to These Operating Principles:

10.1 Any changes to these by-laws must be submitted to a HCAP vote; a majority of votes cast is needed to change these by-laws.

# Example 3.3.4: Terms of Reference for a CBPR Project

### Terms of Reference Contract from the Wellesley Institute

# 1. Purpose of the CBR Project

- One sentence project description: This research project is a community-based study committed to identifying/ understanding/measuring...
- One sentence project goal: The results of this study will be used to enhance quality of life through mobilizing community, building capacities, identifying programmatic gaps, and impacting social policy...
- **Project objectives:** The project will achieve this goal by identifying specific factors that impact on quality of life and will put forth strategies for program enhancement, community-building and policy change

### 2. Guiding Principles for the CBR Project

- This project will engage a set of principles that will foster community ownership and empowerment among team members, including power sharing, capacity building through mentoring and learning exchanges, group participation in all appropriate phases of the research project, and community ownership of the project.
- This project will engage in an open and transparent process where a collective vision of research goals and objectives is shared, and where the roles and expectations of team members are clearly understood;
- · This project will be a collaborative and equitable research partnership where members draw upon individual skill

sets to meaningfully and mutually work toward the team's vision;

- This project will provide opportunities for capacity building through "learning exchanges" where team members can learn about research skills, community development, and community work;
- This project will engage in data analysis interpretation processes that honor the lived experiences/knowledge of community members;
- This project will employ dissemination strategies leading toward education, advocacy, community benefit, and social change;
- This project will foster a supportive team environment through critical reflection of our work and group process.

# 3. Decision-Making Process for the Project

Our decision-making process in this project aims to:

- · encourage the participation and empowerment of all team members;
- · be transparent, open and clear;
- provide opportunities for exchanges of learning that draw on the various skills and areas of knowledge of different team members;
- recognize the responsibilities of the Co-Principal Investigators as Project leaders;
- · recognize the responsibilities of the Project Coordinator as the Project's staff person.

### Differing Responsibilities:

- · Team decisions will include those related to the project's overall goals and strategies;
- Project leaders and staff are responsible for decisions related to the management of the research and administration to the Project.

# **Process for Team Decisions:**

Decision-making at Team meetings will strive first for consensus and then will use simple majority votes

# 4. Access to/Dissemination of Data

Based upon the project's guiding principles, the Co-PIs and the Co-Investigators share ownership and have access to the research data. Usage of the data will be in accordance with the project goals and will adhere to all requirements of the Research Ethics Board at [name of organization(s)]. Data will be used for:

- · advancement of knowledge;
- · identification of future research questions;
- · making recommendations for policy and service provision.

The data should not be for individual interests that are not related to the goals of the research.

In accordance with CBR principles, we are proposing a model of dissemination that encourages the active involvement of all research team members while taking into account their varying responsibilities and capacities. Research findings will be disseminated in various ways including community forums, conference presentations, agency

workshops, newsletters, and journal articles. The Co-Pls, the Co-Investigators, and the Project Coordinator are all encouraged to engage in dissemination of the research findings, and are encouraged to share information about potential dissemination activities.

The Co-PIs will take the initiative in identifying potential journal articles and discussing them with the team. Articles may be written by individuals or by writing groups formed to develop particular manuscripts. All members of a writing group will share authorship on a manuscript. If the paper discusses concerns or issues relating to a particular ethno-cultural community or communities, team members from these communities will be encouraged to participate in the writing group. Order of authorship and mechanisms for feedback on manuscript drafts will be decided up front by writing group members. Groups may also be formed for the development of conference presentations, community forums, and other dissemination activities.

### 5. Process Evaluation

We will regularly chart our progress against our timeline submitted. We will also provide time at then end of each meeting (15 minutes) to review our process. Twice a year, we will hold meetings specifically to debrief about our work. At these meetings we will both critically reflect on our process/outcome balance and make recommendations for adjusting our work accordingly.

# MEMORANDUM OF UNDERSTANDING BY AND BETWEEN THE NATIONAL FRIENDLY ACCESS<sup>SM</sup> PROGRAM OFFICE AND

# THE FOUNDING PARTNERS & THE COALITION STEERING COMMITTEE OF THE COMMUNITY FRIENDLY ACCESS<sup>SM</sup> COALITION

# **PREAMBLE:**

The purpose of this Memorandum of Understanding (MOU) is to clearly delineate the roles and responsibilities of the Founding Partners, the Coalition Steering Committee, the Coalition and the National Program Office in the achievement of Community Friendly Access Project activities and as a requisite for receipt of project funds, resources or other benefits associated with participation in the National Friendly Access Program. This is not a legally binding agreement. In order for the Community Friendly Access Project to succeed, multiple organizations must fulfill their individual project responsibilities as well as those that require collaboration with other member organizations.

The Founding Partners and the Coalition Steering Committee members are the organizing body of the Coalition. They shall consist of executive level representatives of the community institutions responsible for assuring and providing inpatient and ambulatory maternal and pediatric (for ages 0-5) health care for the Medicaid eligible population in the community. The Founding Partners and Steering Committee shall be the signatories of the agreement and shall be responsible for collaborating to achieve the project objectives explained in the body of this document. The membership of the Steering Committee may be revised subsequent to the signing of this Agreement according to the by-laws of the Coalition.

The National Friendly Access<sup>SM</sup> Program Office enters into this agreement with the Community Friendly Access<sup>SM</sup> Founding Partners and the Coalition Steering Committee to jointly continue to further develop, implement and evaluate a Community Friendly Access<sup>SM</sup> Project Model in \_\_\_\_\_\_, building on the accomplishments of the first year of the Project.

# **Background:**

The Lawton and Rhea Chiles Center for Healthy Mothers and Babies received a cooperative agreement from the Centers for Disease Control and Prevention to work in partnership with communities throughout the United States to implement the National Friendly Access Program. The mission of the National Friendly Access Program is to change the culture of maternal and child health care delivery systems in ways that improve consumer access, utilization, satisfaction and outcomes.

Access to, utilization of and satisfaction with maternal and child health care are critical ingredients in improving maternal and child health outcomes. A preliminary review of the literature indicates three factors that may preclude a woman from seeking or continuing to use prenatal services: the physical distance that she has to travel; the psychological distance that she

may feel from her health care providers, and the confusing and frustrating system itself. Impersonal and sometimes offensive treatment of consumers also contributes to consumer dissatisfaction and under- utilization of important preventive services.

The National Friendly Access<sup>SM</sup> Program will partner with Community Coalitions to develop and implement Community Friendly Access<sup>SM</sup> Projects in accordance with National Friendly Access<sup>SM</sup> Maternal and Child Service Guidelines, mission, values, operating principles and expectations.

# The National Friendly Access<sup>SM</sup> Program has the following objectives:

- 1. To create model systems for the delivery of maternal and child health services at the community level in accordance with "Friendly Access<sup>SM</sup> Service Guidelines." Copies of these guidelines are provided in "Building a Friendly Access<sup>SM</sup> Program at the Community Level."
- 2. To build a maternal and child health leadership development and quality service improvement training program for community-based, interdisciplinary teams of service providers addressing the health of mothers, infants, and young children.
- 3. To implement a technical assistance program for community coalitions developing Friendly Access SM demonstration programs.
- 4. To implement a Friendly Access research program that defines problems based on experience and data, investigates solutions, designs interventions to address the problems, evaluates results in community settings, and disseminates "best practices" nationally. The National Program will attempt to answer two core questions in addition to specific questions that may arise from the community projects:
  - Does improving customer service to children and pregnant women increase access to and utilization of health services, both preventive and curative?
  - Does increasing access and utilization improve certain health indicators?
- 5. To develop a holistic approach to the delivery of maternal and child health services by linking health care providers with social, educational, and economic service providers who work with underserved families.
- 6. To build a national dialogue on quality service through national and regional conferences and information exchange on the Friendly Access Website.

# **ROLES AND RESPONSIBILITIES**

The following roles and responsibilities pertain to the signatory partners of this document.

# The National Friendly Access<sup>SM</sup> Program agrees to:

- 1. Provide technical assistance to the Community Friendly Access<sup>SM</sup> Coalition to develop, implement, and evaluate the project.
- 2. Assist the Community Friendly Access SM Coalition in developing and training interdisciplinary teams who will lead the change process within and across their respective agencies and organizations.
- 3. Assist the Community Friendly Access SM Coalition in assessing its maternal and child health service delivery systems to determine their effectiveness with regard to outcomes, availability, access, utilization, quality service, health benefits, and customer satisfaction.
- 4. Facilitate strategic planning focused on determining root causes of problems and implementing strategies based on successful experiences in similar communities.
- 5. Assist the Community Friendly Access<sup>SM</sup> Coalition in designing and implementing maternal and child health service delivery systems and interventions that improve access, utilization, quality service, health benefits, and customer satisfaction.
- 6. Develop and implement competency-based practice curricula to strengthen the skills of practitioners involved in providing the ten essential public health services in support of healthy mothers, infants and young children.
- 7. Establish research programs that will assist public and private maternal and child health care programs and providers in the effective delivery of preventive health care services.
- 8. Create and implement a system for the dissemination of policy and practices emanating from Friendly Access SM Program research and evaluation.
- 9. Identify key variables related to quality maternal and child health service delivery and develop tools to evaluate the process as well as intermediate and long term outcomes of the Project.
- 10. Provide protocols for guiding the Project's research and evaluation studies including a copy of the Data Security Manual of the Lawton and Rhea Chiles Center for Healthy Mothers and Babies, University of South Florida
- 11. Assign a Project Officer to facilitate project implementation and provide technical assistance.
- 12. Provide National Friendly Access SM Communications guidance to assure the appropriate use of the Friendly Access M name, logo and service mark. The Friendly Access M Service mark must be included on all documents made available to the public. The National Program Office will provide communication procedure guidelines regarding press releases and other materials distributed to the public about the program.
- 13. Provide orientation and training for Coalition chair, and other Coalition members as needed.

- 14. Provide training for community internal team members as needed.
- 15. Provide training for a Community Leadership Team of up to seven individuals selected by the Coalition Steering Community. The Team will include the Project Director, the Project Evaluation Coordinator, and five other individuals who will lead and facilitate the community's strategic planning process.
- 16. Build upon, enhance and establish program partners that will assure ongoing support for the Community Projects as well as the National Program.
- 17. Collaborate with the Community Coalition to seek and secure resources needed for the continuation of their Community Project and the National Program, as well as expand the program into additional Communities that demonstrate the capacity and desire to do so.

The National Program Office has created arbitrary labels to distinguish separate structures and processes for assuring critical functions are carried out. It will be the Coalition Steering Committee and the Founding Partners' responsibility to decide if new groups/committee, etc. need to be formed or if existing groups can assume the functions. This document describes the critical functions and responsibilities and the deliverables required.

Each Founding Partner, whose organization provides direct maternal and child health care and eligibility services, agrees to:

Maintain and support an Internal Friendly Access<sup>SM</sup> Team dedicated to the
achievement of the project objectives and activities within their respective
organizations. (Examples of support include release time for Friendly Access<sup>SM</sup>
activities, meeting space, direct communication with management and executive
leaders, etc.)

The internal teams have the following responsibilities:

- 1. To facilitate the established process for developing, implementing, and evaluating strategies for improving consumer access, use, and satisfaction by building quality service within their organizations.
- 2. To facilitate the established process for linking and integrating internal planning and intervention with the strategic plan developed by the Community Friendly Access Coalition.

# Internal Friendly Access<sup>SM</sup> Teams' Structure

Ideally, Internal teams are comprised of individuals in leadership roles in the following functions within their organizations:

Human Resources

- Facilities
- Systems/Operations
- Professional Practice
- Communications

# Internal Friendly Access SM Teams' Responsibilities

- Participate in project training provided by the National Friendly Access SM Program.
- Facilitate the collection of data required for their organization for Friendly Access<sup>SM</sup> project evaluation.
- To the extent possible, analyze and interpret primary and secondary data specific to their own institutions to identify opportunities for improving consumer access, use and satisfaction.
- Participate in "thinking like a marketer" training of Community Friendly Access<sup>SM</sup> provided by the National Friendly Access<sup>SM</sup> Program at the community level.
- Design and implement a quality improvement plan for their organization to address service issues identified in the internal organizational baseline assessment.
- Implement and evaluate the strategies developed in the internal planning process.
- Instill quality service principles and practices in their respective organizations.
- Share with the Community Coalition and the National Friendly Access SM Program strategies developed for improving consumers' access, use, and satisfaction within their organization.
- Share with the Community Coalition and the National Friendly Access<sup>SM</sup> Program activities performed internally within the team and with the Coalition.
- Develop and implement a protocol for linking and integrating internal planning and intervention development efforts with the efforts of the Community Friendly Access<sup>SM</sup> Coalition.

# The Coalition Steering Committee agrees to:

- 1. Submit required status reports/products to facilitate funds being released to the Administrative Coordinator. All reports and products are to be sent electronically directly to the assigned Project Officer with copies sent to the National Program Office and the Administrative Coordinator.
- 2. Comply with policies and procedures established regarding the use of the Friendly Access name and logo.
- 3. Adhere to previously established procedures for hiring, orienting, and supervising Coalition staff
- 4. Utilize an Administrative Coordinator for the Coalition with whom the University of South Florida, on behalf of the National Friendly Access Program can contract to receive funding on behalf of the Coalition.

- 5. Maintain a senior project director, evaluation coordinator, and support staff for data collection and evaluation. The Project Director will report to the Coalition Steering Committee, as distinct from any one of the partners and will have the following functions, at a minimum:
  - Serve as a liaison between the Project and the national technical assistance team.
  - Coordinate the activities of the Coalition partners in support of this agreement.
  - Facilitate the ongoing community maternal and child health data collection for project evaluation and outcome measurement.
  - Document the Project's progress in meeting its expectations and the expectations of the National Program.
  - Supervise the Community Friendly Access SM Coalition staff.
  - Comply with communication protocols and guidelines.
  - Participate in staff orientation and training.
- 6. Assist the National Program Evaluation Team in ongoing community maternal and child health data collection for project evaluation as detailed in the "Preliminary Master Plan for the Evaluation of the Friendly Access" Program."
- 7. Maintain and support the Community Leadership Team to assure the Team's participation in the seminars conducted by the National Program Office. The Community Leadership Team is an interdisciplinary group selected by the Coalition to participate in the Leadership Seminars. The team will consist of the Project Director, the Project Evaluation Coordinator and five other individuals who will lead and facilitate the community's strategic planning process.
- 8. Facilitate the establishment of a data collection process and database to facilitate project research, evaluation and outcome measurement.
- 9. Collect and report project evaluation data according to established protocols and timelines.
- 10. Develop and expand the Coalition as needed for project implementation.
- 11. Continue to implement an action plan developed for the project period that includes:
  - Vision, mission and value statements that are consistent with those of the National Program.
  - Structure and processes for interagency strategic planning to design and implement interventions that will improve access to, utilization of and satisfaction with maternal and child health services in the Project's community.
- 12. Engage Community Quality Service Team members who attended the *Disney* Program in the development of the Friendly Access SM strategic plan.
- 13. Implement a process to conduct root cause analysis and how it might influence the design of interventions and submit a report on the result of that process.

- 14. Report on analysis and interpretation of baseline primary data from consumers and providers.
- 15. Submission of a "community analysis profile" that incorporates analyses of baseline primary data that identifies priority populations and links institutional issues related to service delivery, and detail specific successes and challenges in the access, use, and satisfaction of maternal and child healthcare consumers.
- 16. Draft research plan to learn more about the community priority populations and the issues they confront in accessing care.
- 17. Provide regular reports on work-to-date within Community Friendly Access<sup>SM</sup> Coalitions to plan additional research and interventions.
- 18. Draft strategic plan for addressing changes to the MCH care delivery system at the community and institutional levels.
- 19. Collaborate with the National Program Office to seek and secure resources needed for the continuation of their Community Project and the National Program, as well as expand the program into additional Communities that demonstrate the capacity and desire to do so.

# **Data Management:**

Signatories shall agree that all data will be managed in compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Founding Partners, the Coalition Steering Committee, and Coalition members and staff will comply with policies and procedures as outlined in the Data Security Manual of the Lawton and Rhea Chiles Center for Healthy Mothers and Babies, University of South Florida and in accordance with federal and state regulations. Unauthorized disclosure shall be deemed a breach of this Agreement and Agreement will be subject to termination as detailed below.

# **Intellectual Property Rights:**

Publishing of results that relate strictly to a Community Friendly Access SM Project shall not be subject to approval or restriction by The University of South Florida (USF). However, the Community Friendly Access SM Coalition agrees to deliver to USF any analyses or reports prepared on the results of the Project for scholarly publication at least thirty (30) days in advance of the submission of such proposed publication or presentation to a journal, editor, or other third party for review and comment. Such publications or presentations shall not contain any project-identified proprietary information. In addition, when the results of the research are published, the Community Friendly Access Coalition agrees to provide USF with advance copies of the publication and acknowledge the support received from USF. The parties further agree that upon mutual agreement, employees of USF may co-author publications that relate strictly to the Community Friendly Access Project. Should there be a conflict concerning authorship, final determination shall be made by the Principal Investigator and the National Program Director.

Publishing of results that relate to multiple Community Friendly Access<sup>SM</sup> Projects shall not be subject to approval or restriction by individual projects. However, USF agrees to deliver to

Community Friendly Access SM Coalition any analyses or reports prepared on the results of the Project for scholarly publication at least thirty (30) days in advance of the submission of such proposed publication or presentation to a journal, editor, or other third party for review and comment. Such publications or presentations shall not contain any project-identified proprietary information. In addition, when the results of the research are published, USF agrees to provide the projects with advance copies of the publication. The parties further agree that upon mutual agreement, persons involved in Community Friendly Access Projects locally may co-author publications that address multiple community Friendly Access Projects. Final authority to determine authorship shall be held by the Principal Investigator National Program Director.

# **Modifications to this MOU:**

This Memorandum may be modified with supplemental written agreements signed by the parties and can be terminated in writing in whole or in part, by consensus of the parties.

In the event of termination, the Community Partner and any subsidiary partner to the Project may not use the Friendly Access<sup>SM</sup> name, logo or affiliation in any of its publications or communications for internal or external consumption.

# Required Deliverable Due Dates for the Second Year (August 2003 through July 2004):

# October 31, 2003

A summary of project activity for August, September, and October with attachments to include:

- Statement of Project Vision, Mission, and Values developed by the Jacksonville Friendly Access<sup>SM</sup> Initiative
- Submit community access and use data statements based on initial examinations of secondary data
- List of individuals who participated in the September Leadership Seminar in Atlanta
- Report on status of ongoing primary data collection, entry, and if applicable local analysis.
- Report on training and technical assistance requested and received from the National Friendly Access SM Program Team

# January 31, 2004

A summary of project activity for November, December, and January with attachments to include:

- Draft list of critical issues, preliminary root cause analysis, and priority issues
- Draft of interventions and investment strategies including the logic model
- Draft Strategic Plan
- Report on status of ongoing primary data collection, entry, and if applicable local analysis.
- Report on training and technical assistance requested and received from the National Friendly Access SM Program Team

# **April 30, 2004**

A summary of project activity for February, March and April with attachments to include:

- Status of Implementation of Community Strategic Plan
- Status report on Internal Teams Progress focus on interventions designed to improve consumers' access and use that are not necessarily included in the Jacksonville Friendly Access<sup>SM</sup> Initiative Strategic Plan
- Report as to the structure (new or existing) and processes (new and existing) that will achieve the objectives of the "internal teams"
- Report on status of ongoing primary data collection, entry, and if applicable local analysis.
- Report on training and technical assistance requested and received from the National Friendly Access SM Program Team

# August 31, 2004

A summary of project activity for May, June, July and August with attachments to include:

- Progress and analysis report on Implementation of Community Strategic Plan
- The teams, their membership and roles in their institutions, their activities to date, how they relate to the Steering Board and Leadership Committee, how they have begun to integrate the Disney training into their site, and technical assistance needs they may have for the coming year.
- The Leadership Committee's role in strategic planning, their activities to date, how they relate to the Steering Board and Leadership Committee, how they have begun to integrate the Disney training into the community strategic planning process, and technical assistance needs they may have for the coming year.
- Efforts and accomplishments in engaging and involving pediatric and child care providers and related representatives in the activities of the project.
- New or changed insights about goals and outcomes from the project a discussion of what the Jacksonville Friendly Access SM participants and staff learned as well as what they did.
- List of individuals who participated in the Spring Leadership Seminar
- Report on training and technical assistance requested and received from the National Friendly Access SM Program Team
- Proposed Budget and Work Plan for Year 03
- Recommendations for the National Office for the upcoming year

This Memorandum of Understanding is entered into within the limits of the statutory authority of the parties to the Memorandum			
Understood and Agreed:			
Delores F. Jeffers, RN, MPH	Peter A. Gorski, MD, MPA		
University Project Director	Professor and Center Director		

Lawton and Rhea Chiles Center for Healthy Mothers and Babies University of South Florida Lawton and Rhea Chiles Center for Healthy Mothers and Babies University of South Florida

The following Founding Partners and members of the Steering Committee jointly agree to the roles and responsibilities delineated in this Memorandum of Understanding:

Founding Partners:	
Print Name and Title:	
Print Name and Title:	
Print Name and Title:	
Print Name and Title:	
Print Name and Title:	
Print Name of Agency:	
Print Name and Title:	
Print Name of Agency:	
Signature:	
Founding Partners:	
Print Name and Title:	
Print Name of Agency:	

# MEMORANDUM OF UNDERSTANDING FOR THE COMMUNITY ORGANIZING PART OF COMMUNITY ACTION AGAINST ASTHMA

# 1-22-01

This is a Memorandum of Understanding between the University of Michigan School of Public Health, Detroiters's Working for Environmental Justice (DWEJ), the Detroit Hispanic Development Corporation (DHDC) and Warren Conner Development Coalition (WCDC). For the purposes of this Memorandum, these agencies will be called "host agencies." This Memorandum of Understanding sets forth the working relationship of these organizations including their roles and responsibilities as a part of their involvement in the community organizing part of Community Action Against Asthma, hereafter called CAAA.

**Philosophy/Principles:** Throughout the term of this partnership, these partner organizations agree to abide by the philosophy and principles spelled out in the Detroit Community Academic Urban Research Center's "Community-Based Public Health Research Principles" adopted on July 24, 1996, agreed upon by the Community Action Against Asthma Steering Committee on December 16, 1998, and listed here:

- Community-based research projects need to be consistent with the overall objectives of the Detroit
  Community-Academic Urban Research Center (URC.) These objectives include an emphasis on the
  local relevance of public health problems and an examination of the social, economic, and cultural
  conditions that influence health status and the ways in which these affect life-style, behavior, and
  community decision-making.
- 2. The purpose of community-based research projects is to enhance our understanding of issues affecting the community and to develop, implement and evaluate, as appropriate, plans of action that will address those issues in ways that benefit the community.
- 3. Community-based research projects are designed in ways which enhance the capacity of the community-based participants in the process.
- 4. Representatives of community-based organizations, public health agencies, health care organizations, and educational institutions are involved as appropriate in all major phases of the research process, e.g., defining the problem, developing the data collection plan, gathering data, using the results, interpreting, sharing and disseminating the results, and developing, implementing and evaluating plans of action to address the issues identified by the research.
- 5. Community-based research is conducted in a way that strengthens collaboration among community-based organizations, public health agencies, health care organizations, and educational institutions.
- 6. Community-based research projects produce, interpret and disseminate the findings to community members in clear language respectful to the community and in ways which will be useful for developing plans that will benefit the community.
- Community-based research projects are conducted according to the norms of partnership: mutual
  respect; recognition of the knowledge, expertise, and resource capacities of the participants in the
  process; and open communication.
- 8. Community-based research projects follow the policies set forth by the sponsoring organization regarding ownership of the data and output of the research (policies to be shared with participants in advance). Any publications resulting from the research will acknowledge the contribution of participants, who will be consulted with prior to submission of materials and, as appropriate, will be

invited to collaborate as co-authors. In addition, following the rules of confidentiality of data and the procedures referred to below (Item #9), participants will jointly agree on who has access to the research data and where the data will be physically located.

9. Community-based research projects adhere to the human subjects review process standards and procedures as set forth by the sponsoring organization; for example, for the University of Michigan these procedures are found in the Report of the national commission for the Protection of Human Subjects of Biomedical and Behavioral Research, entitled "Ethical Principles and Guidelines for the Protection of Human Subjects of Research" (the "Belmont Report").

Adapted from Schulz, AJ, Israel, BA, Selig, S, and Bayer, I. 1997. Development and Implementation of Principles for Community-Based Research in Public Health. Journal of Community Practice.

**Program Objectives to be Accomplished:** The following are specific aims and objectives as stated in the grant as it was funded. CONEH refers to the community organizing activities of CAAA.

<u>Specific Aim 1:</u> To identify, prioritize and translate the relevant findings of the current CAAA data collection activities, together with proposed, additional CONEH data collection activities, to guide the implementation and evaluation of an expanded, community-wide intervention.

Objective 1: To identify specific sources of particulate matter (PM) and their association with childhood asthma severity.

Objective 2: To identify and prioritize the relevant findings of the CAAA project to guide the CONEH.

Objective 3: To translate the priority areas selected into intervention action plans to guide the CONEH.

Specific Aim 2: To conduct and evaluate a multi-level community-based intervention in order to reduce exposure to physical environmental and psychosocial environmental stressors associated with asthma severity and exacerbations, and to strengthen protective factors (e.g., social support, community capacity) that may modify the effects of these stressors.

<u>Objective 1</u>: To identify and engage existing community-based organizations, groups, institutions and agencies in an Inter-Organizational Network to address identified priorities.

<u>Objective 2:</u> To reduce identified physical environmental and psychosocial environmental stressors through community organizing intervention activities.

<u>Objective 3:</u> To strengthen neighborhood protective factors, such as social support and community capacity, through community organizing intervention activities.

<u>Objective 4:</u> To increase the capacity of organizations involved in the I.N. to work collectively to reduce physical and psychosocial environmental health hazards and strengthen protective factors associated with asthma.

<u>Specific Aim 3</u>: To examine whether the conducted multi-level, community-based intervention enhances the effect of an intensive household intervention on the health and well being of children with asthma and their caregivers.

<u>Specific Aim 4</u>: To increase community awareness and knowledge of factors associated with the environment and asthma through the dissemination of research findings to community residents in ways that are understandable and beneficial to the community.

**Dates for this Memorandum of Understanding**: The grant project period is from 9-18-2000 to 7-31-2005. This memorandum is intended to cover the entire grant period.

# Responsibilities of the University of Michigan, School of Public Health:

- 1. Actively support the CAAA partnership.
- 2. Participate in the CAAA partnership through membership in the Steering Committee. Communicate with the Steering Committee members regarding administrative and programmatic issues related to the community organizing project in Detroit.
- 3. Provide overall program oversight.
- 4. Collect data, conduct preliminary analyses of existing and new data, and provide feedback to all partners and to staff as appropriate.
- 5. Provide financial and programmatic reports to the funder, NIEHS (National Institute of Environmental Health Sciences.
- 6. Serve as a point of contact with NIEHS.
- 7. Assist in the staff hiring process.
- 8. Develop and conduct an orientation to the project for partners and staff.
- Work with the community organizers and administrative assistant in planning and conducting community forums.
- 10. Provide co-supervision of community organizing staff with each of the host organizations.
- 11. Serve as the fiduciary agent for this project. Pay the bills, dispense funds (see "Financial Arrangement" for more details).
- 12. Assist in providing resources and technical assistance in activities supporting the design and implementation of assessment, data collection, and evaluation systems.
- 13. Assist in the dissemination of results to the community.
- 14. Ensure that there is ongoing communication between the host organizations and the University of Michigan by sharing information regularly and frequently.

# Responsibilities of Detroiters Working for Environmental Justice:

- 1. Actively support the CAAA partnership.
- 2. Participate in the CAAA partnership through membership in the Steering Committee. Communicate with the Steering Committee members regarding administrative and programmatic issues related to the community organizing project in Detroit.
- 3. Develop and conduct an orientation to DWEJ for all community organizing staff.
- 4. Provide co-supervision of Environmental Policy/Community Organizer and the Administrative Assistant with the University of Michigan School of Public Health.
- 5. Provide office space for staff assigned to DWEJ.
- 6. Facilitate communication and linkages between DWEJ and other community organizations and groups.
- 7. Provide 10% of a staff person's time to serve as the "Host Agency Liaison." The responsibilities of this person will include:
  - Participating in the hiring of the community organizing staff using a process to be approved by the CAAA Steering Committee;
  - Participating in an orientation to the overall community organizing project;
  - Providing an orientation and integration of the Environmental Policy/Community Organizer and the Administrative Assistant to the organization;
  - Providing co-supervision of the Environmental Policy/Community Organizer and the Administrative Assistant. This would include day-to-day supervision to ensure attendance and adherence to the agency's policies, and oversight and assistance in his or her conduct of day to day job responsibilities as per the job descriptions.
- 8. Assist in providing resources and technical assistance in activities supporting the design and implementation of assessment, data collection, and evaluation systems.
- 9. Meet deadlines to ensure that the reporting process for the grant is a timely one.
- 10. Participate in the process of analyzing and translating the data collected to guide the efforts of the community organizers.

- 11. At all times, assure that the community organizers are carrying out their responsibility to focus on the community, with the goal of seeking ongoing, continuos input from the community.
- 12. Assist in the dissemination of results to the community.
- 13. Ensure that there is ongoing communication between the host organizations and the University of Michigan by sharing information regularly and frequently.
- 14. Provide necessary training on an ongoing basis to community organizing staff and Administrative Assistant.

# **Responsibilities of Detroit Hispanic Development Corporation:**

- 1. Actively support the CAAA partnership.
- 2. Participate in the CAAA partnership through membership in the Steering Committee. Communicate with the Steering Committee members regarding administrative and programmatic issues related to the community organizing project in Detroit.
- 3. Develop and conduct an orientation to DHDC for all community organizing staff.
- 4. Provide co-supervision of Neighborhood Community Organizer housed in DHDC with the University of Michigan School of Public Health.
- 5. Provide office space for staff assigned to DHDC.
- 6. Facilitate communication and linkages between DHDC and other community organizations and groups.
- 7. Provide 10% of a staff person's time to serve as the "Host Agency Liaison." The responsibilities of this person will include:
  - Participating in the hiring of the community organizing staff using a process to be approved by the CAAA Steering Committee;
  - Participating in an orientation to the overall community organizing project;
  - Providing an orientation and integration of Neighborhood Community Organizer to the organization;
  - Providing co-supervision of the Neighborhood Community Organizer. This would include day-to-day supervision to ensure attendance and adherence to the agency's policies, and oversight and assistance in his or her conduct of day to day job responsibilities as per the job descriptions.
- 8. Assist in providing resources and technical assistance in activities supporting the design and implementation of assessment, data collection, and evaluation systems.
- 9. Meet deadlines to ensure that the reporting process for the grant is a timely one.
- 10. Participate in the process of analyzing and translating the data collected to guide the efforts of the community organizers.
- 11. At all times, assure that the community organizers are carrying out their responsibility to focus on the community, with the goal of seeking ongoing, continuos input from the community.
- 12. Assist in the dissemination of results to the community.
- 13. Ensure that there is ongoing communication between the host organization by sharing information regularly and frequently.
- 14. Provide necessary training on an ongoing basis to community organizing staff.

# **Responsibilities of Warren Conner Development Coalition:**

- 1. Actively support the CAAA partnership.
- 2. Participate in the CAAA partnership through membership in the Steering Committee. Communicate with the Steering Committee members regarding administrative and programmatic issues related to the community organizing project in Detroit.
- 3. Develop and conduct an orientation to WCDC for all community organizing staff.
- 4. Provide co-supervision of Neighborhood Community Organizer housed at WCDC with the University of Michigan School of Public Health.
- 5. Provide office space for staff assigned to WCDC.
- 6. Facilitate communication and linkages between WCDC and other community organizations and groups.

- 7. Provide 10% of a staff person's time to serve as the "Host Agency Liaison." The responsibilities of this person will include:
  - Participating in the hiring of the community organizing staff using a process to be approved by the CAAA Steering Committee;
  - Participating in an orientation to the overall community organizing project;
  - Providing an orientation and integration of Neighborhood Community Organizer to the organization;
  - Providing co-supervision of the Neighborhood Community Organizer. This would include day-to-day supervision to ensure attendance and adherence to the agency's policies, and oversight and assistance in his or her conduct of day to day job responsibilities as per the job descriptions.
- 8. Assist in providing resources and technical assistance in activities supporting the design and implementation of assessment, data collection, and evaluation systems.
- 9. Meet deadlines to ensure that the reporting process for the grant is a timely one.
- 10. Participate in the process of analyzing and translating the data collected to guide the efforts of the community organizers.
- 11. At all times, assure that the community organizers are carrying out their responsibility to focus on the community, with the goal of seeking ongoing, continuos input from the community.
- 12. Assist in the dissemination of results to the community.
- 13. Ensure that there is ongoing communication between the host organization by sharing information regularly and frequently.
- 14. Provide necessary training on an ongoing basis to community organizing staff.

# **Financial Arrangements:**

Each of the community partners involved in the Community Organizing part of CAAA: DWEJ, DHDC, and WCDC will receive funds from The University of Michigan, School of Public Health for services rendered as host agencies, as a part of this agreement. For year one, each agency will received \$13,000. There will be a slight increase each year (e.g., \$13,200 for year two, \$13,408 for year three). These funds are for community field costs, which include:

Liaison – 10% x 3 locations	\$15,000
Facilities Rental x 3 locations	9,000
Community Organizing Activities	
x 3 locations	11,100
Field Ofc. Supplies	1,200
Copying, printing	900
Telephone	1,200
Postage, express mail	600

Total Community Field Costs \$39,000 divided by three = \$13,000 each

To obtain the funding, after staff is hired, each agency will submit an invoice for the first six months of the first year, or \$6,500. An invoice for the second six months will be submitted five months later. It will take approximately one month from the time the University of Michigan receives the invoice for it to be processed and for the agencies to receive the funding. Agencies do not need to keep a detailed track of the expenditures as a part of this agreement.

The University of Michigan School of Public Health will also provide a computer at a cost of no more than \$2500 for each of the four staff persons hired.

# **Memorandum of Understanding Amendments:**

The agreement shall be renewed annually by the signatories.

# **Termination of Memorandum of Understanding:**

This agreement may be terminated by either party provided not less than thirty days (30) written notice of intent to terminate is given and an opportunity for prior consultation is provided.

In the event of termination, accounts shall be reconciled as of the date of termination.

Signatures:	
This Memorandum of Understanding is entered in	to on(date)
(signatures)	
	_(for the University of Michigan, School of Public Health)
	(for Detroiters Working for Environmental Justice)
	(for Detroit Hispanic Development Corporation)
	(for Warren Conner Development Coalition)

On February 14, 2006 the Executive Board of Directors of the Mendocino Cancer Resource Center passed a resolution by majority vote to accept the terms of the proposal to the California Breast Cancer Research Program on ownership of data, handling disagreements, grant award and contract, dissemination plan, and community applicant responsibilities as follows:

# Ownership of Data:

We are instituting a Data Sharing Plan, (see

http://www.research.ucsf.edu/cg/cg\_DataSharing.htm) which will make the data (stripped of patient identifiers) available to any interested community member or researcher, at the conclusion of an embargo period (2 years) designed to allow us to submit articles to peer-reviewed journals. Within our research team, during the two-year embargo period, the three co-Principal Investigators by majority vote will make any decisions involving data distribution. We made this decision because we believe that scientific data belongs in the public domain.

# **Handling Disagreements:**

We strive first to find consensus amongst ourselves, and through community input and the advice of our colleagues and mentors. If that fails, either one of the co-PIs may request mediation from our mediator Marilyn Johnson of Lake County Dispute Resolution Services. Our decision-making process in case of disagreements is first working toward consensus. However, we have made a commitment to seek mediation for any decision on which we are unable to reach agreement.

# **Recipient of Grant Award:**

The grant award will be received by each partner separately. The award will be divided equally between UCSF and the Mendocino Cancer Resource Center. The award will be \$600,000 in full for the grant period of 36 months. It is understood by the Board of Directors of the Mendocino Cancer Resource Center, Inc, that MCRC will hold it's own contract as will UCSF.

# **Dissemination Plan:**

The Board of Directors and the Co-PI will prepare quarterly progress reports to members of the community advisory board during the project period, and members have agreed to be available for individual consultations and briefings. Members include: community health leaders; primary care physicians; breast care specialists; members of the public, including past clients; and resource center staff and volunteers. Because this Full Study aims to improve our referral network for breast cancer patients, we will be in constant communication with people in the community to ensure that every person facing breast cancer during our study period is referred to us. These interactions will provide ample opportunities for briefing community members on what we're doing and getting their feedback. In addition to the local dissemination strategies, the partnership will also submit papers to medical journals that have previously published our studies (such as the Journal of Clinical Oncology and the Oncology Nursing Forum), or would be suitable for this topic (e.g. Health Services Research, and Medical Anthropology Quarterly.) The Academic Co-PI will take the lead on preparation of these publications.

# **Community Applicant:**

It is understood that the organization, the Mendocino Cancer Resource Center, Inc., if awarded the grant, is the community applicant and has ultimate responsibility for the carrying out of the project plan. In the event that the named Community Principal Investigator will not be able to continue her duties in the capacity of Co-PI, the executive board will appoint a successor and submit that successor's name and credentials to the California Breast Cancer Research Program Director for approval.

Signed (Agency Official)	
Date	