



**Rutgers** Center for  
State Health Policy

*The Institute for Health, Health Care Policy, and Aging Research*

# **OMMH Grantees 2004 - What Have We Learned?**

**Denise A. Davis, Dr.P.H., M.P.A**

**Sabrina Chase, Ph.D.**

**July 2005**





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## Acknowledgements

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# **OMMH Grantees 2004 – What Have We Learned?**

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## **Executive Summary**

### ***Description of the Project***

This report summarizes the results of a study to assess the experiences of the last cohort of the Office of Minority and Multicultural Health (OMMH) grantees in identifying, screening, educating and referring vulnerable, hard-to-reach populations for health care in local communities. This study was commissioned by the New Jersey Office of Minority and Multicultural Health to assess grantee activities specifically working in the area of diabetes. The goal of the study is to identify valuable lessons learned from OMMH grantee programs that can inform future grant-funded projects. Study findings suggest that the inclusion of community based organizations in community focused collaboratives can improve involvement of minority populations in screening and treatment initiatives.

### ***Summary of Methods***

OMMH staff identified four grantee organizations within which interviews were to be conducted. Three of these grantee organizations identified and targeted solely Hispanic community populations among whom to conduct outreach and screening while one grantee organization focused on African Americans at risk for diabetes. The purpose of the key informant interviews was to identify promising grantee practices and note interesting program issues that could be further investigated in planned focus groups. Telephone interviews were conducted with one key informant per identified grantee organization. Findings from these interviews were then used by the research team to re-define the interview protocol for use in the second phase of the study, the focus groups. The focus group interview guide focused on targeting and capturing program strengths, weaknesses, and lessons learned over the funding period. Two large grantee organizations identified by OMMH staff to be most successful among grantees participated in the focus group phase of the study.

Both key informant interviews and focus groups were conducted by CSHP research staff in order to:

- A. Identify successful and unsuccessful strategies mounted in local community-based organizations in efforts to meet OMMH program criteria

- B. Assess common themes
- C. Identify unexpected benefits for communities of program findings
- D. Identify unexpected consequences for grantee communities; e.g., barriers to collaboration, referrals, prescription access, etc.
- E. Provide grantee recommendations for next steps based on existing program experiences to date
- F. Document lessons learned
- G. Identify major project themes across participating grantee organizations

## **Findings**

### ***Key Informant Interviews***

All grantee programs focused on diabetes outreach within their community, provided blood pressure screening, patient education, referrals and patient follow-up. Program effectiveness was quantitatively measured by the number of persons attending monthly events held, the number of screenings performed, and referrals provided. Strategies noted as being most effective include the use of grocery store coupon incentives for program participants, the provision of free glucose test strips, and support group sessions conducted at convenient times for community residents.

Broad themes noted from the interviews include the importance of community level collaboration, the value-added of CBO inclusion in program initiatives, and the challenge of program sustainability post OMMH funding. The collaborative relationships developed by grantees over the course of this program initiative were highlighted by many informants as making a significant difference in overall program success. Entities participating in the collaborative as noted by all grantee informants include a community church, a community health center or clinic, the local hospital and a representative of the local municipality (e.g., the health department or another city agency). In addition, key informants of the community-based organizations (CBOs) funded all agreed that their organizations provide program value that is immeasurable but essential to overall program success. Informants noted that CBOs communicate well with vulnerable patient populations, share cultural experiences with those in the community, can and have built trusting relationships with community members and groups, can identify community needs and garner resources within the community to meet the identified need. The collective opinion of all informants was that these organizations really can and do make a difference in community resident lives. In the instance of this grant program, grantees

were firm on the impact of CBOs regarding program success but clearly vulnerable on long-term program sustainability once the grant funding ended.

## **Focus Groups**

### ***Measures of Program Success***

Participants of the focus groups corroborated the findings of the key informants. These groups provided greater detail on the measures noted in the previous interviews (e.g., noted program successes, identified collaborating organizations, described barriers and facilitators to access to care, discussed the value of CBO-run initiatives, and the challenges associated with long-term sustainability).

In particular, focus group participants discussed the importance of accessibility, concordance and an inviting, caring attitude and trust in the patient-provider relationship. Equally important issues noted by grantees include:

- 1) The development of the relationship at the clinical level among willing providers, and
- 2) The need for a provider working within the CBO to open the door for patients through his/her dialogue with another provider so that patients can see providers interested in their care.

Another valuable service that CBOs provide to community members is case management of patients or clients. This service is often essential to the continuation of care seeking by vulnerable populations but not always provided to these patients by local providers particularly if these providers do not operate in a closed network.

### ***Recommendations to OMMH for next steps***

Grantee study participants suggested that OMMH continue funding to the communities that they serve. In addition, there was an overall agreement that linking patients to providers is a role that CBOs can fill and new state-funded initiatives should include and promote CBO-clinical provider collaboratives in the future.

Findings from this study suggest that in order to effectively address disparities within minority communities, the State must develop community-focused intervention models that include CBOs. In addition, adequate methods of measurement to assess the value of the work these entities perform, such as identifying and screening hard-to-reach-populations, educating patients about disease conditions, connecting them to clinical providers, and ensuring patient

continuation in care plans should be identified. Based on the noted experience of the existing grantees, a number of program areas require strengthening. Specific recommendations for future initiatives include:

- Development of a standardized tool for future data collection across all grantees of patients: 1) identified and screened, 2) educated about chronic disease and case managed, 3) provided with health care system navigation skills, 4) educated on lifestyle changes and decision-making /problem-solving skills, and 5) provided with ongoing social supports.
- Reporting of program outputs ( including patient follow-up) within a twelve month period thus allowing for mid-course program corrections as needed
- Continued use of qualitative methods to assess program activities over time (e.g., conduct key informant interviews and focus groups across grantees)
- Development of a case study model inclusive of “patient story” and “provider story” formats that can be documented and shared
- Identification of specific problem areas or issues unique to minority populations when seeking and/or receiving care from providers
- Creation of “model lessons from the field” that work in persistent problem areas for program adoption and replication.

# OMMH Grantees 2004 – What Have We Learned?

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Denise A. Davis, Dr.P.H., M.P.A., Sabrina Chase, Ph.D.

## Introduction

Health disparities are differences in the incidence, prevalence, mortality, and burden of disease on specific population groups as compared to others. When assessing the health status of African-Americans, Native Americans, Hispanic Americans and other minority groups, particularly in the area of chronic disease, research documents that these groups shoulder a greater burden of disease than Whites within the United States. Despite major medical advances and numerous enhancements to the public health system that have helped to improve the health status of most Americans in this country, African-Americans and many other minority groups continue to suffer an unequal burden of death and disease, particularly regarding preventable chronic illnesses (Silva, Whitman, Margellos et al. 2001; Levine, Foster, Fullilove, et al. 2001; Cooper, Kennelly, Durazo-Ariviluz et al. 2001; Guest, Almgren, and Hussey. Feb 1998). Excess morbidity and lower life expectancy continues to plague minorities much more than non-minorities and this appears to be highly resistant to change. Persistent health gaps that characterize many chronic diseases such as HIV/AIDS, cancer, diabetes, asthma, coronary heart disease and cerebrovascular disease have been documented by decades of research but an overarching explanation explaining why certain groups continue to shoulder a disproportionate burden of negative health outcomes is unclear (Byrd and Clayton, 2000, 2001).

As in other states within the union, the state of New Jersey has documented persistent differences in disease rates for chronic conditions between white and non-white populations for several years (Healthy NJ 2000, Healthy NJ 2010). In fact, in several areas, the incidence of disease for minority populations has been rising within the state at an alarming rate (Boeselager, 2001; NJ Department of Health and Senior Services, Center for Health Statistics Diabetes Fact Sheet). In an effort to better identify vulnerable populations with chronic conditions and poor access to care at the community level, the New Jersey Office of Minority and Multicultural Health (OMMH) developed a grant initiative focused on engaging community groups and coalitions working with populations known to be at risk for diabetes, asthma and coronary heart disease. This OMMH initiative awarded grants to ten community-level organizations in June 2002 to improve community awareness of chronic disease, promote better access to care, encourage and increase health seeking behavior, suggest long-term lifestyle changes among community members, coordinate services for uninsured and underinsured individuals, and provide ongoing

case management. Grants awarded for this three-year period were to address disparities among minority populations that presented to community-based organizations with chronic health care conditions and by so doing, model best practices that prove successful in addressing diabetes in communities of color. Ultimately, lessons learned from these demonstrations can be used in future programs focused on improving the health outcomes of New Jersey's minority populations who suffer from this chronic disease.

## **Goal of Funding**

The strategy engaged by OMMH funding of local grantees was to foster collaboration across community-based organizations (CBOs) and clinical providers, increase community level education and awareness of prevalent chronic diseases, promote improved health seeking behaviors and improved health lifestyle choices among residents, and create a more coordinated system of care for community-level consumers through primary care linkages and case management. The grantee awards funded demonstration programs developed by community-based organizations and coalitions to provide successful outreach, education and screening to local at-risk, hard-to-reach minority populations. The ability of grantees to meet proposed population targets as well as attain the program's goals of providing patient referral, follow-up and case management where appropriate, is of particular interest to OMMH in this initiative. In order to meet these goals, grantees were required to collaborate with local clinical providers, develop trusting relationships with other community organizations and leaders (e.g., faith-based and civic organizations), and establish linkages to community residents. In addition, to insure accurate diagnosis capability within community-based organizations, in-house clinical personnel were hired and grantees established ongoing relationships with local pharmaceutical companies for continual access to testing devices and discount medications. The OMMH grants give grantees wide latitude in the formation of strategies, techniques and innovative program enhancements based on the leader's assessments of targeted community-level needs.

## **Overview of the Report**

This report is the result of an assessment of this initiative to ascertain whether the OMMH grantee program has met its goals. To conduct the program assessment, OMMH contracted with the Rutgers Center for State Health Policy (CSHP) to document and review the impact of grantee initiatives focused specifically on diabetes awareness, at-risk population identification, screening activities, community outreach and individual education and referral. To accomplish this task, CSHP research staff have drawn on a number of different sources of data. The primary source of data on the experiences of grantees is a series of key informant interviews that outline specific

activities and accomplishments of the individual projects. In order to provide more in-depth information on grantee initiatives deemed successful by OMMH staff members, two in-depth focus groups with the leadership of suggested programs were also conducted. These focus groups provided identification of specific programmatic activities, challenges encountered, and innovative strategies undertaken by grantees to support community clients. Finally, grantee informants and focus group participants provide recommendations to OMMH about program sustainability post grant funding as well as suggestions for future initiatives focused on disparities.

The information culled from these data sources allows the CSHP research staff to provide a preliminary look at these grantee activities, the particular accomplishments achieved by each grantee and those individual as well as collective challenges encountered. The report is organized around the following major themes: collaboration activities, program markers of success, measurable criteria of program effectiveness, barriers to access to care, the value-added of CBO-run initiatives, program sustainability and recommendations to OMMH. In addition, within the report, we provide some small “snapshots” of particular grantee activities.

## **Background**

In recent years, states have experienced a rapid rise in the incidence of chronic diseases, many of which are related to both physiological and lifestyle factors. Over the last 20 years, obesity, caused by sedentary behavior and poor diet; has increased dramatically (Centers for Disease Control, 2001), as have health problems caused by tobacco and other drug use (Coalition for the Advancement of Health Through Behavioral and Social Science Research, 2004). In 2004, nearly 125 million Americans were living with one or more chronic conditions such as heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer’s disease (Coalition for the Advancement of Health Through Behavioral and Social Science Research 2004). However, as a group, racial and ethnic minorities disproportionately experience serious disparities in access and health outcomes particularly as relates to particular chronic conditions (Institute of Medicine, 2002).

Diabetes (particularly type II diabetes) is a chronic disease that has been shown to disproportionately affect minority populations within the United States (Luchsinger 2001; Harris 1998). From 1980 through 2003, the age-adjusted prevalence of diagnosed diabetes was higher among Blacks than among Whites and highest among Black females ([www.CDC.gov](http://www.CDC.gov)). Research also shows that rates of diabetes increases with age among both men and women. Given the aging population in the United States, diabetes has become the sixth leading cause of death

among all groups in the United States. However, African-Americans are twice as likely as Whites of similar age to develop it (National Cancer Institute – Diet-Related Chronic Diseases that Disproportionately Affect African American Men). While prevalence varies among Latino subgroups, it ranks as the fifth leading cause of death for Latinos overall, compared to the seventh cause of death for the general U.S. population (Luchsinger, 2001). Research also indicates that once the disease has manifested, African Americans are more likely to develop complications and experience greater disability. Death rates from diabetes are 27% higher for African Americans than for White Americans; the former develop diabetic eye disease at a 40 to 50 percent higher rate than the latter and they are 4 times more likely to experience kidney failure (National Cancer Institute – Diet-Related Chronic Diseases that Disproportionately Affect African American Men). Diabetes and its related complications account for large numbers of inpatient and outpatient health care visits that over the course of the disease, can prove extremely costly to the patient and create an added drag on the health care system (Thorpe et al., 2005).

According to 1999-2001 Behavioral Risk Factor Surveillance System (BRFSS) data estimates in New Jersey, minorities are at the highest risk of developing diabetes. Minorities are also affected by the disease at younger ages, thus leading to long-term disease complications. Although numerous minority individuals are affected by diabetes, many go undiagnosed (BRFSS). Genetic factors such as insulin metabolism, overweight, obesity, insulin resistance and low levels of physical activity are all issues that have been shown to impact particular racial and ethnic subgroups differently in shaping the current diabetes ‘epidemic’ (Luchsinger 2001). In addition, issues of culture, family background and the availability of social supports influence health. Thus, both clinical and cultural issues should be examined on a case-by-case basis when attempting to generate initiatives that reduce the disparity gap in the case of diabetes.

In funding this initiative, OMMH sought to identify promising disparity reduction programs that include:

- Racial and Ethnic Data Collection and Tracking
- Patient Education and Outreach
- Screening and Referral
- Follow-up and Case Management

Specifically, through funding such demonstration projects, OMMH hopes to identify best practice models for addressing health care disparities in minority communities. By fostering



collaboration and partnership across providers of care and CBOs, it is hoped that significant improvement in access to care, care delivery and social supports occur that subsequently trigger positive impacts on outcomes of minority populations, which in turn can be documented.

## **Project purpose**

OMMH contracted with the Rutgers Center for State Health Policy (CSHP) to conduct an assessment of purposeful sample of grantees from the OMMH community-level initiative for improving the health of New Jersey's minority populations. In particular, this investigation was to focus on grantee organizations engaged in diabetes outreach, screening, education and referral, and assistance or support in ongoing diabetes management. The study's goal is to identify grantee and program-specific barriers and facilitators and document all best practices for possible future application.

In the initial phase of the study, CSHP research staff reviewed grantee-specific proposals, assessed grantee-identified population targets, and periodic progress reports. The second phase of this study involved primary data collection through key informant interviews and focus groups of OMMH grantees. Two-semi-structured interview protocols were developed for this purpose. The first protocol was a telephone interview guide used in the key informant interview process and the second protocol developed was used with focus groups conducted in this study. Both guides consists of four specific content areas of focus: perceived program effectiveness, the importance of community level partners or collaborators, program achievements, successes and outcomes and long-term sustainability post OMMH funding. Additional questions posed in each instance queried grantee participants on significant organizational challenges and successes experienced during OMMH project funding. Finally, grantees were asked about next steps for new funding initiatives focused on narrowing the disparity gap between minority and non-minority populations. It is expected that this study's findings will assist OMMH in promoting future successful grant demonstrations by providing the agency with detailed knowledge about approaches that work well at the community level.

## **Methods**

This study used a two stage qualitative research design. The first stage involved key informant interviews of identified leaders and / or administrators of community-based organizations. The second stage involved focus groups of key representatives within OMMH identified funded grantee organizations. In both instances, OMMH staff provided the CSHP research team with a convenience list of grantee organizations that met pre-established program

volume requirements. This group of grantees is the focus of this study investigation. Semi-structured data collection instruments were developed for use in both stages (Appendix 1 & II).

OMMH staff identified four grantee organizations within which interviews were to be conducted. To insure anonymity throughout this report, these grantees will be referred to as AA, BB, CC and DD. Three of these grantee organizations identified and targeted Hispanic populations while one grantee organization focuses on African Americans who are diabetics. The purpose of the four key informant interviews was to identify promising practices and note similar themes or issues that required more specific focus in the second phase of the study. A member of the CSHP research team conducted telephone interviews with one key informant per identified grantee organization. Findings from these interviews were then used by the research team to re-define the interview protocol for use in the second phase of the study, the focus groups. The focus group interview guide focused on targeting and capturing program strengths, weaknesses and lessons learned over the funding period. Two large grantee organizations suspected by OMMH staff to be most successful among grantees and who possessed unique characteristics that warranted further investigation, participated in the focus group phase of the study.

Key informant interviews were conducted by phone and CSHP research staff took notes from these discussions. All telephone interviews generally lasted 20 to 30 minutes. Data collection resulted from interview notes taken during the discussion. Next, focus group sessions were conducted in-person at two of the grantee locations. Both focus groups were recorded and data reviewed in order to:

- A. Identify successful and unsuccessful strategies mounted in local community-based organizations in efforts to meet OMMH program criteria.
- B. Assess common themes
- C. Identify unexpected benefits for communities of program findings
- D. Identify unexpected consequences for grantee communities; e.g., barriers to collaboration, referrals, prescription access, etc.
- E. Provide grantee recommendations for next steps based on existing program experiences to date
- F. Document lessons learned

Major project themes were then identified across the participating grantee organizations.

## **Limitations**

Purposeful samples of study participants were used for both key informant interviews and focus groups. Given study time constraints, the interview protocol questions were limited in the number and depth of question areas. Also, it is possible that the program experiences or geographic and social environments of other grantees not included in the data collection process could be different than those reported in this study. Finally, absent a specific data collection tool to measure definitive patient outcomes and periods of program effectiveness, much of this study's analysis is limited to a descriptive level.

## **Findings**

### ***Key Informant Interviews***

Grantees all focused on outreach to vulnerable populations in their geographic areas, particularly African-Americans, Haitians, South Americans and other Hispanic groups. Using the American Diabetes Association ten-point scoring test as a screening tool, all key informants met their program targets (e.g., 1000 patient screenings per year or 12 outreach events conducted per year) within the second year of state funding. The use of this tool also allowed identification of high risk patients who were then targeted for ongoing patient education, counseling, referral to help groups, clinicians and program follow-up.

All grantee programs focused on diabetes outreach within their community, provided blood pressure screening, patient education, referrals and patient follow-up. Program effectiveness was quantitatively measured by the number of persons attending monthly events held, the number of screenings performed, and referrals provided. Strategies noted as being most effective include the use of grocery store coupon incentives for program participants, the provision of free glucose test strips, and support group sessions conducted at convenient times for community residents.

Broad themes noted from the interviews include the importance of community level collaboration, the value-added of CBO inclusion in program initiatives, and the challenge of program sustainability post OMMH funding. The collaborative relationships developed by grantees over the course of this program initiative were highlighted by many informants as making a significant difference in overall program success. Entities participating in the collaborative as noted by all grantee informants include a community church, a community health center or clinic, the local hospital and a representative of the local municipality (e.g., the health department or another city agency). In addition, key informants of the community-based

organizations (CBOs) funded all agreed that their organizations provide program value that is immeasurable but essential to overall program success. Informants noted that CBOs communicate well with vulnerable patient populations, share cultural experiences with those in the community, can and have built trusting relationships with community members and groups, and can identify community needs and garner resources within the community to meet the identified need. The collective opinion of all informants was that these organizations really can and do make a difference in community resident lives. In the instance of this grant program, grantees were firm on the impact of CBOs regarding program success, but clearly vulnerable in terms of long-term program sustainability once the grant funding ended. A synopsis of key informant findings from these interviews is provided in Appendix III.

## Focus Groups

### *Measures of Program Success*

Participants of the focus groups corroborated the findings of the key informants. These groups provided greater detail on the measures noted in the previous interviews (e.g., noted program successes, identified collaborating organizations, described barriers and facilitators to access to care, discussed the value of CBO-run initiatives, and the challenges associated with long-term sustainability). The following provides a comparison of grantee focus groups on program success measures.

OMMH Grantee	BB	DD
Program target goal met	Minimum of 1000 per quarter	Minimum of 2500 per year
Program clinicians engaged	Two registered nurses (one a diabetic) from the community vested in educating and providing service to community members to assist them in better management of this chronic condition.	Physician and nurse practitioner from the community working for the CBO to ensure patients of clinical access, health education and individual training in disease management.
Program Success Markers	Overwhelming participation of community members in diabetic cooking classes. Diabetics in the program are either part of a support group or maintain a “one-on-one” relationship with the program nurses.	Early signs of patient education payoff. Many patients have begun to show signs of improvement through: weight management (e.g., increasing weight loss) lower blood pressure readings resulting from weight loss continued follow through on diabetes education
Criteria best showing program effectiveness	The number of newly identified diabetics that have been screened, tested, educated, and referred. Upon follow-up all patients are still engaged with the program.	Number of patients where lifestyle changes can be documented thus demonstrating high level of program participant uptake.

Discussions with focus group DD were particularly interesting when participants were asked how they knew the program was effective. Specifically we asked them:

- 1) Are these programs effective in changing patient behavior?
- 2) How are these programs measured?

One clinician from focus group DD replied:

“How do I know that monies provided to CBO’s are being actively used and the dollars provided have been well invested. There is data to justify this program investment. Using a person with diabetes – there is a measurable outcome can be used to measure a diabetic four times a year— Hemoglobin A-1C. And if we can measure that number and show that : a) having the person educated about diabetes, b) having the person exercise regularly and lose those ten pounds, c) having them go to their regular physicals and d)stay on their medication; all these things will provide a measurable outcome.”

### **Barriers to Access to Care**

A number of barriers to care were identified by both focus groups. Participants from focus group BB highlighted the lack of health insurance by community members, the rising cost of out-of-pocket care, bias and unwelcoming attitude of clinicians in hospitals toward minority individuals, the lack of diabetic programs in inner city areas, and the cost of medications as significant barriers to patient access to care. One diabetic nurse participant described the impact of medication costs on a patient she sees.

“Many persons are just about the poverty level. Insulin costs \$128/ bottle, not to mention the added cost of syringes and test strips. I, for example, take insulin 4 times a day—this is a very expensive disease. I have a patient who squeezes her insulin— she either cuts her dosage in half or only takes one full dose per day as opposed to the two the physician has prescribed for her. My heart goes out to her because she just makes enough money that she cannot get insulin. She doesn’t make enough money that she can afford this. It shouldn’t be that way— there is an imbalance here.”

Individuals from focus group DD spoke more about the complete disconnect between existing providers of care (e.g. hospitals and diabetes trained nursing staff) and community-

based organizations engaged in outreach and screening. One participating physician who works in a CBO stated,

“They knew of each other but there was no communication between these two programs and the patients were not getting the care. I don’t believe that making a connection with the hospital source that you get the success that we have experienced with the combination of the two.”

This same participant when queried about models that have been effective within communities indicated,

“The only difference between the model existing here and the other models is that you have a physician on board— I’ve seen it in Connecticut and New York. A lot of hospitals have the right attitude and want these programs to work but they just can’t get the patients to come. There is that distrust and that disconnect. A CBO with a physician from the community with the same background as those individuals, I think that’s the winning combination. That is what has gotten patients there—we have always met our contract goals, in fact, we have exceeded them – it’s word of mouth. We were able to bridge that gap, between the services that existed and the need that was there. I don’t believe that the program would work if you put the money directly into the hospitals and told the CBO’s, here you form collaboration. I think you need an in-between guy ( a bridge) someone who can bridge the gap, someone who can be trusted, someone who can speak and be an advocate for the community as well. [In this program,] we got doctors together to do that.”

### **Value added of CBO-run initiatives**

Participants were asked about the value-added of their programs. Specifically the question posed was:

What is the value added provided by Community Based Organizations (CBOs) when addressing disparity issues among minority populations?

Focus group BB participants noted the importance of accessibility, concordance and an inviting, caring attitude. This sentiment was well stated by one person in the group,

“We’re not judging, we just want to help, cultural attitude -- people of color no matter where you come from are people of color. People can identify with you because it’s the same culture, same color.”

A DD focus group member put it this way, “the most essential thing about a CBO is that ‘they are on the ground.’

Focus group DD members also spoke about the importance of trust in the patient-provider relationship.

“.....we had a Hispanic physician who they were able to trust as well as what we [the CBO] were able to tell them. This could not have been done at a federal level or even through an ad campaign at a national level. You won’t reach the right people or they won’t believe you.”

Equally important issues noted by grantees include:

1. The development of the relationship at the clinical level among willing providers and
2. The need for a provider working within the CBO to open the door for patients through his/her dialogue with another provider so that patients can see providers interested in their care.

Another valuable service that CBOs provide to community members is case management of patients or clients. This service is often essential to the continuation of care seeking by vulnerable populations but not always provided to these patients by local providers particularly if these providers do not operate in a closed network.

### **Greatest challenges**

Both focus group participants identified the cost of prescription drugs for patients as a huge challenge. When describing her frustration with this problem, one of the nurses commented, “It’s nice to diagnose somebody and then, they have this new information but they just can’t help themselves.” Another participant indicated that in his program, they have been



able to get some free drugs from pharmaceutical companies. However, access to prescriptions is still viewed as problematic for many persons in the program.

Overcoming physician's perceived negative attitude toward minority patients was noted as another major challenge. The participating physician in the focus group put it this way,

“Non-minority physicians truly believe that minority populations do not get it or they just don't care about their health care. My personal experience as a physician is that they honestly believe that. White physicians think, “If I tell this patient exactly about the disease and instruct them what to do, why is it that the minority patient will not listen and the Caucasian patient does?”

The participating physician indicated that he thought this could be a language barrier (at least with the Hispanic patient). It could be a matter of trust. He stated that physicians generally believe minority patients don't get it or don't care and this is based on their [minority patients] outcomes not being positive.

This physician provided a further example of what he has observed with colleagues in medical practice,

“For example, a physician has two patients, one white, one Hispanic and one patient's hemoglobin A-1C goes down and the other one doesn't. It must be because the Hispanic patient is not taking his medication. It probably has nothing to do with the fact that he [the physician] was able to discuss it a lot clearer with the Caucasian patient [about] what medications he needed to take and the reasons why. This is the difference and when they [physicians] don't see success, they don't feel the encouragement at trying to go further so the next Hispanic patient they encounter, they say what's the point?”

A final challenge noted by focus group participants is the ability to get more diabetic males in for screening, testing and referrals for treatment. According to these focus group participants, many males are still not willing to admit they are diabetic or at risk for the disease.

## **Greatest successes**

Two very different successes were identified by grantee participants. One group highlighted their success in getting a particular male into testing. Once in the program, this individual attracted other at-risk males and acted as role model for those already in the program. Nurses touted this as a major success story for the community.

Members of the other focus group discussed the provision of program data to the Johnson & Johnson Corporation. Participants hoped that the company might have an interest in funding the program's operations post the OMMH funding period.

## **Recommendations to OMMH for next steps**

Grantee participants suggested that OMMH continue funding to the communities that they serve. There was an overall agreement that linking patients to providers is a role that CBOs can fill and the state needs to expand initiatives that include and promote CBO-clinical provider types of collaborative relationships in the future. One participant suggested that there be:

“a focus on prevention and education. This is the cheapest thing that we can do as far as funding is concerned where we can do the most good. If we avoid the problem, before it becomes a problem, we can cure these people and they'll never have this disease at home. First go to the state level and focus on the young people— the people who are 16, 17, 18 years old recruit them into the care of their parents and it's easy. The Hispanic and Latino community will lend itself to that because they are family-based oriented. This is an easy thing to do and it will be very cost-effective.”

When discussing how CBOs can play a major role in future program initiatives targeted at eliminating disparities, one participant stated that,

“Minority CBOs (especially those that have 20 to 25 year history) are investments placed into the community by the citizenry of that community. These community-based organizations are viewed as part of the community (not entities from outside). **When we provide services to clients, it's because they want them.** They come here because of issues of language, cultural competency, trust, basically even as a sounding board. It's a family— a close-knit group of people that come together and are comfortable with each other and trust the information they are receiving and can act on it because of that trust. And you are not going to find that kind of relationship when your try to institutionalize it.

The idea of having organizations that have this relationship with the community is that people, institutions and providers want to serve. We should be working in tighter relationships and giving the CBOs more capacity through the institutions that are mainstream providers; not competing with them but adding capacity to them, especially when working with mono-lingual populations.”

## **Discussion**

Most key informant and focus group participants are in agreement that trust between patients and providers is an essential factor for vulnerable populations in seeking care and continuing to actively participate in care plans. Given the trust relationships developed between community members and CBO grantees through this funded initiative, it is clear that any new programmatic efforts should include this element if expected to be successful. Qualitative evidence from this project supports the importance of involving community-based organizations in programs structured to identify “hard-to-reach” minority patients, connecting them to primary caregivers and insuring continued patient participation in developed care plans. The CBOs were viewed by project participants as acting as “bridgers” between the gap in services that currently exist and the identified need in the community. These entities were also described as “in-between persons” who can be trusted and act as advocates for the community. Finally, the CBOs were described by study participants as occupiers of roles that no other entity could fill. They alone were in the unique position of guiding and assisting mainstream providers in the long-term management and treatment of minority populations. In order for main-stream health care organizations to become more “in-step” with minority populations, now as well as in years to come, it was recommended by participants that collaborative relationship models including CBOs, clinicians, and local health care organizations be developed. In this way “innovative interventions that work” to thwart existing health care disparities can be developed and replicated across local communities.

## **Conclusions**

Findings from this study suggest that in order to effectively address disparities within minority communities, the State must develop community-focused intervention models that include CBOs. In addition, adequate methods of measurement to assess the value of the work these entities perform, such as identifying and screening hard-to-reach-populations, educating patients about disease conditions, connecting them to clinical providers, and ensuring patient continuation in care plans should be identified.

## Recommendations

Based on the noted experience of the existing grantees, a number of program areas require strengthening. Specific recommendations for future initiatives include:

- Development of a standardized tool for future data collection across all grantees of patients: 1) identified and screened, 2) educated about chronic disease and case managed, 3) provided with health care system navigation skills, 4) educated on lifestyle changes and decision-making /problem-solving skills, and 5) provided with ongoing social supports.
- Reporting of program outputs ( including patient follow-up) in twelve month periods thus allowing for mid-course program corrections as needed
- Continued use of qualitative methods to assess program activities over time (e.g., conduct key informant interviews and focus groups across grantees)
- Development of a case study model inclusive of “patient story” and “provider story” formats that can be documented and shared
- Identification of specific problem areas or issues unique to minority populations when seeking and/or receiving care from providers.
- Creation of “model lessons from the field” that work in persistent problem areas for program adoption and replication.

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# Appendix I

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## Telephone Interview Guide – OMMH Grantee Project – 3/30/05

The mission of the Office of Minority and Multicultural Health (OMMH) is to foster accessible and high-quality programs and policies that help all racial and ethnic minorities in New Jersey achieve optimal health, dignity and independence. OMMH will accomplish this mission through increasing public and health professional awareness of persistent race/ethnic disparities and providing funding intended to support demonstration projects that will model best practices in addressing persistent health conditions that are prominent within minority populations. Through such initiatives, effective health policies and culturally competent programs may be developed that lead to better access and utilization of quality health care services.

As a first step in assessing the promise of OMMH funded initiatives, interviews of current OMMH grantees are being conducted to document effective strategies and useful programmatic lessons in narrowing the disparity gap. Of particular interest are the grantee activities associated with increasing diabetes awareness, screening/identification of undiagnosed diabetics, linking potential patients to healthcare services, providing self-management techniques ongoing patient tracking and monitoring capabilities.

Name of Organization \_\_\_\_\_ Interviewee name & title \_\_\_\_\_  
Date of Interview \_\_\_\_\_ Interviewer name \_\_\_\_\_

### Program

Please state the focus of your organization. \_\_\_\_\_

Please describe the program for which you were funded by OMMH (e.g., program intent)

\_\_\_\_\_

For what period of time has your program been funded? \_\_\_\_\_

What chronic disease area are you targeting with your program? \_\_\_\_\_

What initial benchmarks were established to determine program effectiveness?

\_\_\_\_\_

Was there a population target set (#'s of pts reached) at the commencement of your program?

\_\_\_\_\_

If so, in what period of time were you able to reach it?

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If not, what other measures were used to assess program effectiveness?

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How does your program track process data?

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How does your program track and access outcome data?

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What selection criteria was used in identifying potential patients?

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What patient information do you collect at intake?

---

Do you collect patient follow-up data at any time?

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Can you provide a copy of your data collection instrument?

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What specific program activities/aspects have you found to be most effective and useful?

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Please explain why?

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### **Collaboration**

Please list the names of your collaborators/community level partners

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Is there any one collaborator that plays an integral part in this initiative?

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If so, can you describe in what way?

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What roles do other collaborators play?

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Does your organization have prior experience in this targeted program area?

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If so, please explain in detail

---

Please list the providers with whom your organization is affiliated.

---

How many staff members are engaged in this initiative?

---

(# of FTE's covered by the grant?)

**Outcomes**

Please describe patient educational programs provided by your organization

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Are these programs effective in changing patient behavior?

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How are these programs measured?

---

Has your program created lasting links between patients and providers?

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If so, how is this information captured?

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What other information should have been captured but was not?

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What is the value added provided by Community Based Organizations (CBOs) when addressing disparity issues among minority populations?

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What suggestions would you make for future OMMH funding of these types of initiatives?

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## Appendix II

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### Focus Group Guide

#### **Program Questions**

Please describe the program for which you were funded by OMMH (e.g., program intent).

What initial benchmarks were established to determine program effectiveness?

Was there a population target set (#'s of pts reached) at the commencement of your program?

#### **Collaboration**

Is there any one collaborator that plays an integral part in this initiative? If so, can you describe in what way? What roles do other collaborators play?

What is the value added provided by Community Based Organizations (CBOs) when addressing disparity issues among minority populations?

#### **Outcomes**

Please describe patient educational programs provided by your organization. Are these programs effective in changing patient behavior? How are these programs measured?

#### **Sustainability**

How will your program be sustained post OMMH funding?

#### **Other Probes**

What are the greatest challenges your organization has faced? What did you do about them?

What are your organizations' greatest successes? How were they created? Who was involved?

Why was this project so successful? Where do you think your organization should go next?

What suggestions would you make for future OMMH funding of these types of initiatives?

## Appendix III

<b>OMMH Key Informant Grantee Interview Findings – June 2005</b>			
<b>Issue Area</b>	<b>Grantee Organizational Participants in Key Informant Interviews</b>		
	<b>AA</b>	<b>BB</b>	<b>CC</b>
<b>Targeted population</b>	Latinos in Elizabeth at risk for diabetes (most un-documented immigrants with no insurance)	Members of churches predominately in the East Orange area (predominately African-Americans, Haitians, Africans, and South Americans)	Hispanics in Essex County
<b>Set target</b>	1000 screenings/yr: target met after second year.	12 outreach events per year: target met at the second quarter of the third year	1000 screenings/yr: target met in the last year of funding
<b>Individual Selection Criteria</b>	American Diabetes Association- 10 point test - scoring of 10 points or more are referred and tracked	American Diabetes Association- 10 point test - scoring of 8 points or more are referred and tracked	Initially finger pricks, then switched to American Diabetes Association- 10 point test – high risk score of 10 points or above are referred and tracked
<b>Program Focus</b>	Outreach program focused on diabetes. Provided screenings, education and referrals.	Provide outreach and diabetes education for community members. Also provide screenings, exercise programs, counseling and referrals as required.	Increase awareness in the community through diabetes education, screening and outreach. Also provided referral where required.

**OMMH Key Informant Grantee Interview Findings – June 2005 (cont.)**

Issue Area	Grantee Organizational Participants in Key Informant Interviews		
	<b>AA</b>	<b>BB</b>	<b>CC</b>
Strategies used that proved most effective	Use of grocery store coupon incentives; use of free test strips, health education	Creation of the support group, education and outreach activities	Education sessions
Collaborators	St. Joseph’s church, City of Elizabeth, EPORT clinic, Trinitas Hospital	East Orange Health Department, Newark Community Health Center, East Orange Branch Clinic	UMDNJ Hospital, La Casa de Don Pedro, Newark FQHCs
Data captured	Patient information collected at intake (including name, address, SS # (if they have it), address, sex, monthly rental payment)	Patient information requested on the intake form and anecdotal	General patient contact information
Program value-added	CBOs can communicate with the community patient population and share cultural experiences. Uniquely understands the functioning of the community and thus establishes a trust with all community members.	CBOs can communicate with the community patient population and share cultural experiences. Uniquely understands the functioning of the community and thus establishes a trust with all community members.	CBOs can communicate with the community patient population and share cultural experiences. Uniquely understands the functioning of the community and thus establishes a trust with all community members.
Sustainability post- OMMH	Will seek more funding from a variety of sources and will collaborate with the Eport clinic	Will seek financial assistance from Faith-based organizations and other interested community organizations	Looking for additional funding sources