Community Empowerment



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Community/University Collaboration in Health Care Planning: A Case Study

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With

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Introduction

This article describes a participatory action research project to plan health and social services for elderly, low-income, African American, urban residents. The research team included thirteen academically based health care providers and two social scientists, and thirteen African American residents from the target neighborhood. The specific objective of the project was to develop services consistent with the concepts of Community Oriented Primary Care.

Community Oriented Primary Care

Community oriented primary care (COPC) is a framework for organizing, delivering, and monitoring the effectiveness of primary care for a defined target population. Developed by two South African physicians and used in the United States since the 1960s, the COPC approach is a model for developing health care programs for low-income, medically underserved populations. Thus, establishing a COPC involves (1) defining and characterizing a target population; (2) identifying priority health care problems in the population; (3) mounting intervention strategies or modifying practice patterns; and (4) monitor-

ing the impact of interventions (Mayfield & Grady, 1990; Nutting, 1990). These steps are best achieved when representatives of the target population are actively involved through participatory action research.

Participatory Action Research (PAR)

The basic requirement of participatory action research is that

... some of the people in the organization or community under study participate actively with the professional researcher throughout the research process, from the initial design to the final presentation of results and discussion of their action implications. (Whyte, 1991, p.20).

Whyte emphasizes that PAR avoids treating members of organizations and communities as passive subjects, who participate only to the extent of authorizing a project, being its subjects, and receiving its results. He also points to the contrast between PAR and the type of applied research in which researchers serve as professional experts, designing the project, gathering the data, interpreting the findings, and recommending action to the client organization.

Whyte identified the roots of PAR in social research methodology, quality of work life studies in the 1940s and 1950s, and in the sociotechnic framework that emerged in the 1950s. There is a tension, which has long existed between pure and applied research. Pure researchers argue that researchers should aim at discovering scientific facts or relationships and not get directly involved in linking social research to action. They argue that others will make use of the researchers' findings.

Adherents of PAR believe that it is important to the advancement of science and the improvement of human welfare to devise strategies in which participant and researcher are closely linked. They require an obligation to demonstrate how this collaboration can be established, and also to demonstrate that their research advances knowledge and produces results without sacrificing scientific standards.

Community Roots of the Research

The target population for this project resided in the Stop Six community which is located in southeast Fort Worth. Their quest for a health clinic began nearly two decades ago. Members of the community, led by an influential local minister, the Rev. E. L. Bowman, approached a local philanthropic foundation for seed money to establish a neighborhood clinic. Working with the foundation and the Tarrant County Hospital District

(TCHD), the community eventually garnered funds from the Robert Wood Johnson Foundation (RWJ). However, a planning committee, appointed by TCHD that worked to develop the clinic, was not drawn from Stop Six and did not know the area well. Consequently, when the clinic was built, it was located in an adjacent neighborhood that was culturally different from Stop Six. It was also difficult for Stop Six residents to access this clinic. As a result, the Stop Six neighborhood residents did not use it.

From the point of view of Stop Six, therefore, a new initiative was required. It came in the fall of 1989, when the University of Texas at Arlington School of Nursing, the Texas College of Osteopathic Medicine (TCOM, a part of the University of North Texas Health Sciences Center), and the University of North Texas (UNT) began a collaborative effort to respond to an initiative from the Kellogg Foundation to establish a teaching clinic in a low income. medically underserved neighborhood in Fort Worth. The principal investigator on the Kellogg project—a nurse practitioner at the School of Nursing—formed an advisory board that consisted of the heads of philanthropic foundations, social service agencies, and health care facilities located in Tarrant County. Stop Six was chosen as the target neighborhood for a project based upon a recommendation from a United Way study of health care in Tarrant County that identified Stop Six as the most medically underserved neighborhood in Fort Worth (UWMTC, 1989).

The nurse practitioner also approached the Fort Worth City councilman who represented that neighborhood and requested his assistance in forming an advisory board that would represent neighborhood residents. The city councilman agreed, provided that the universities and the TCHD would agree in writing to continue their commitment to providing health care for Stop Six if the Kellogg project was not funded. The universities and TCHD agreed to this request.

The Stop Six Community Board was formed and included both active and retired professional members of the community. It included teachers, school principals, education counselors, physicians, ministers, lawyers, and a justice of the peace. Most of the board members, however, were not actually residents of Stop Six, but rather, of the more affluent middle- and upper-middle-class neighborhoods immediately adjacent to Stop Six, especially the Carver Heights neighborhood. Carver Heights had been developed in the late 1950s and 1960s, when an African American developer invited some of his friends to buy property in the hilly, heavily wooded area next to Stop Six. Ultimately, some 200 middle- and upper-middle-class

homes were constructed in this area. Many of the community board members had been active in the civil rights movement as community organizers and political leaders. Furthermore, when the civil rights movement ended *de jure* and *de facto* segregation of housing in Fort Worth, these affluent African Americans chose *not* to move away to predominantly white suburbs and neighborhoods.

Most of the community leaders spent part or all of their professional careers working with the residents of Stop Six. Consequently, this cadre of professionals was able to articulate the concerns of the community and to serve as effective advocates for the Stop Six neighborhood. They are highly respected within their community where they are viewed as a source of knowledge and wisdom. Their ability to cope with Jim Crow laws, segregation, and the subtle racism of the 1980s and 1990s makes them a source of inspiration in their community in sharp contrast to many inner city minority communities where middle- and uppermiddle-class African Americans have moved away, leaving a leadership vacuum (Wilson, 1987). They were particularly concerned about the welfare of older residents, whom they perceived to have been hardworking, honest, and family-oriented wage earners.

Although the Kellogg grant was unsuccessful, the effort had begun a process that resulted in the eventual funding of a community health center in the neighborhood. In September 1990, following the failure of the grant effort, the Stop Six Community Board was incorporated as Stop Six Community Services, Inc. (SSCS), which lost no time in reminding the academic institutions and the hospital district of their promise to continue to work toward establishment of a community-based health care clinic. In response, TCOM, UNT, and TCHD continued to work with the community to seek funds for a community oriented primary care clinic in the neighborhood. Based on their past experience with the Robert Wood Johnson supported clinic, the SSCS Board insisted that the community have ultimate control over the planning process, including the location, architectural design, services offered, and personnel hired. However, the Board was expanded to include representatives of the three partners from outside the neighborhood-TCOM, UNT, and TCHD—as ex officio members.

The primary neighborhood targeted for this project is known as Old Stop Six. This area coincides with two census tracts that were state-designated as medically underserved. Although these two census tracts were the primary target, Stop Six Community Services believed that the clinic might draw patients from broader area, which was referred to as Stop Six to distinguish it from Old Stop Six.

The major characteristics of the neighborhood, as identified by the U.S. Bureau of the Census in the 1989 Southeast Fort Worth Health Services Report prepared by United Way of Metropolitan Tarrant County (Sept., 1989), are as follows. The neighborhood covers approximately four square miles and includes five census tracts. In 1980 it had 16,170 residents but only 15,765 in 1990, a decline at a time when other areas of the city were growing. These residents were found in approximately 5,000 households, an average of 3.3 person per household. Almost half of the households had an annual income of less that \$15,000 and most of the residents were African American. The population was relatively young, with approximately one-quarter less than 15 years of age, and less than ten percent 65 years of age or more. The average number of years of school completed was 11.9. With 3,000 people unemployed, occupation and employment data reflected a consistent pattern of economic disadvantage in Stop Six compared to the other Fort Worth neighborhoods.

Eighty percent of the dwellings were single family homes, which varied from well-kept brick structures to dilapidated, boarded up structures. There was little commercial or business development. The main streets of Stop Six were maintained satisfactorily because there were major and minor bus routes, but feeder streets were in need of major repair. Many streets lacked sidewalks and curbs, and throughout the area there was evidence of open lots that serve as dumping grounds. Crime statistics were particularly high, especially crimes of violence.

On a positive note, Stop Six includes four elementary schools, two middle schools, one high school, and one community school. Three of the schools were magnet schools, meaning that they received special support to offer selected programs. This neighborhood is also the home to over 75 churches, or about one for every 200 residents.

During the planning for the unsuccessful Kellogg proposal, a potential need for 62,000 annual primary care visits in the five Census tracts had been estimated. Existing primary care health services included health department pediatric and obstetric clinics. These services accounted collectively for 30,000 annual visits. Primary care services in close proximity to Stop Six include a private family practice and a TCOM practice clinic, which together provided a total of 5,000 annual visits by Stop Six residents. Thus, an unmet need for approximately 25,000 to 30,000 primary care visits in Stop Six was estimated.

Community Strengths

The neighborhood strengths identified during the planning process included the following: the presence of a

caute of strong, experienced, committed leaders who have spent most, it not their entire lives, in or adjacent to Stop Six; a powerful network of churches and ministers who were deeply embedded in the social and spiritual fabric of the neighborhood; several established residential areas with a stable core of homeowners; important relationships between neighborhood leaders and key community leaders; neighborhood awareness of and consensus about major problems and issues; an intense concern of elders about the serious problems of youth in the neighborhood; many residents with deep family ties that bound them to the neighborhood; strong, creative school programs; expressed interest and support by school officials to open their doors to new programs and services for their students; and a strong sense of social responsibility on the part of many residents who are willing to act on behalf of the neighborhood. All of these strengths were reflected among the community representatives on the SSCS Board.

The site chosen for the health center with the advice of the Board was on a major through street on the eastern boundary of the community. Money to purchase the land for the site was obtained through a community development block grant from the City of Fort Worth to the Stop Six Community Services, Inc. University researchers, working with the SSCS Board who provided the ideas for the health center programs, wrote the community development block grant. With the land purchased, TCHD and TCOM both were interested in being the primary care providers in the health center. Eventually, the community decided that the tax support available from TCHD would provide most secure funding for the health center and TCHD was chosen as the funding partner. With the land acquired and the provider chosen, the Board focused its energies on planning the services that would be included in the health center.

Health Needs Assessment Research

Four major health care studies in Tarrant County in the 1980s had demonstrated unmet health needs in this community. The most recent was "Health Care in Tarrant County, 1988" (Harris and Associates, 1988). Drawing on these previous studies, a United Way Task Force concluded that, based on the unmet need for health services, there needs to be "a creative, client centered, comprehensive approach to (health) services, including (a) family planning and reproductive health care, family practice care, maternal health services, prenatal services and well baby care; and (b) case management services to facilitate follow-along and follow-up services, including social services" (United Way of Metropolitan Tarrant County, Sept., 1989, p.7).

A series of focus group interviews with neighborhood senior citizens centers, ministers/church congregations, and Neighborhood Advisory Councils, conducted in the Fall of 1990 by the Kellogg grant planning team, in collaboration with the community, reaffirmed that prenatal care and infant and child care were major health concerns in the neighborhood, but added elderly care as a third major concern. That concern led to participatory action research designed to more clearly delineate the health needs of elderly residents of Stop Six.

Participatory Action Research with the Older Adult Population

Focus on the elderly was critical for this community. Four of the five census tracts in the Stop Six neighborhood had greater percentages of elderly than the population of Tarrant County as a whole. As compared to the approximately nine percent of the county population of Tarrant County that was 65 years of age or older, the percentages in four of the target census tracts ranged from eleven to eighteen percent in that age group. Furthermore, the Stop Six elderly were economically vulnerable. For example, in Census Tract 1036.01, which covers the heart of the Old Stop Six neighborhood, 72 percent of the families had annual incomes below \$15,000 a year and 37 percent of the population had incomes below the official poverty level.

The academically based researchers approached the community in the Fall of 1991 when they learned that there would be competitive intramural research grants available to faculty at the University of North Texas and the Texas College of Osteopathic Medicine to conduct research on older persons. They believed that the community would benefit from a needs assessment that could be used as the basis for asking for services for elderly in the community. Specifically, the goal was to focus on the health care and social service needs of the elderly in Stop Six as a part of the COPC process of identifying priority health problems as a basis for devising intervention strategies.

As noted above, the members of the SSCS Board were concerned about the elderly residents of Stop Six. They agreed for the researchers to develop a research proposal that would be presented to the Board for review. It was also agreed that if the Board did not approve the proposal, it would not be submitted for funding. A Research Committee was formed that included researchers and community representatives. It met weekly to discuss the research proposal and when the research proposal was finalized it was submitted to the full Board for review.

The proposal called for a social survey that included a

questionnaire designed to secure information on four areas of special importance to the elderly living in Stop Six: (1) health and social service needs, (2) health care and social service utilization, (3) family support systems, and (4) community problems. The survey instrument was to be a modified version of the National Health Interview Survey (NHIS) of 1984 that had a special Supplement on Aging (SOA) that contained detailed questions on the health and social service needs of the elderly (National Center for Health Statistics, 1986). The major advantages of using this questionnaire as a model was that the reliability and validity of the items were well established and that findings in the target community could be compared with national and state data.

Community Tensions

When the researchers met with the Board to review the final proposal before submitting it for funding, they sensed tension among the community members at the meeting. There was little of the usual chitchat, community members seemed reluctant to make eye contact, and the researchers were questioned very closely about the proposal. Questions were asked about how the sample would be selected, who would know the names and addresses of the community members who were interviewed, and whether or not physical evidence of health would be collected from the community members. The researchers responded to all these questions, indicating that they were open to negotiation with the community members concerning any research issues.

After several minutes of questioning, the researchers were told that the evening before a program had been shown on television about the Tuskegee syphilis experiment (Jones, 1981). This experiment had been conducted from the 1930s until the 1960s by public health officials in Alabama with the cooperation of faculty at the Tuskegee Institute. It had been designed to study the effects of untreated syphilis among African Americans in Alabama, but the subjects had been led to believe that they were being treated during the course of the study. Even after safe, relatively inexpensive antibiotic treatment became available following World War II, the participants were not given treatment. This television program had alarmed the members of the community, who had never considered the possibility that the researchers might deliberately deceive them and deliberately harm the older people of the neighborhood.

The researchers reacted by assuring the Board members that they had no such intentions. They agreed that the Board would have complete control to keep such

an incident from happening. In addition, the Board members would be free to stop the research at any time. The community Board agreed to consider the issues involved for one week and to decide at the next meeting what course of action to take. Fortunately, the Board decided to approve the research going forward with some modifications to assure the safety and anonymity of the older adults surveyed, an action that the Board endorsed.

One of the modifications was that some of the members of the Board would serve as interviewers for the survey, which assured the protection of the identity of the elderly respondents. Additionally, the Board members were already familiar with the neighborhood, sensitive to its culture, respectful of the older people, and concerned for their well-being. These characteristics would make them strongly motivated interviewers and would increase validity of the responses to the questions.

Ideally, this research project would have used a random sampling technique, but the neighborhood's high crime rate made it likely that many elderly residents would be reluctant to allow strangers to enter their homes. Also, the Board members who had volunteered to serve as interviewers were afraid to go to unfamiliar homes. Therefore, the researchers worked with the members of the Stop Six Community Services to solicit volunteers from the community. Churches, elementary school children in the neighborhood, senior citizens groups, the Fort Worth Housing Authority, and community leaders were all used to obtain a list of elderly persons who were willing to be interviewed. The sample can thus be criticized for its lack of representativeness. However, the researchers felt that this was an important compromise to ensure collaboration of the community leaders, without whom the research could not have been conducted. Volunteers were recruited from as broad a range of community residents as possible to minimize bias due to excluding particular groups of residents from the pool of potential respondents.

The community Board members compiled a master list of all names and addresses secured from these four sources mentioned above. As a part of the revised research design agreed to by the Board and the researchers, the researchers never saw the list of volunteers or the list of the people who were actually interviewed. The residents selected for the sample were contacted by letter to describe the nature of the research and to inform them that they would be contacted by an interviewer for an appointment. As an incentive to participate, they were offered \$5.00 for their participation. If there were refusals, new names were added until 100 residents were interviewed.

I ne Board memoers were paid \$25 per completed interview to compensate them for their time and effort in completing the interviews.

This anecdote about the effect of the television program on the research process illustrates some of the most important lessons learned from this project: trust can never be taken for granted. It requires time and patience to develop and must be constantly nurtured. The keys to establishing trust are honesty and a willingness to compromise. In the long run, the university researchers believe that the compromises to secure the community's trust increased the quality of the research. We believe that the increased validity of the responses to the questionnaire outweighed the loss of a random survey.

The anecdote also illustrates that applied researchers must be sensitive to the experiences of the research participants. Subjectivity and objectivity are not neat and separate categories; they are matters of degree that underscore the PAR process. The PAR model suggests that researcher's objectivity involves a deliberate effort to be conscious of one's own biases. This is translated into acknowledgment of covert assumptions that may be brought to the surface by new developments in the research process. Moreover, the PAR model demonstrates that social reality has many layers of meaning and that human behavior is more complex than it seems. The researcher's discovery of each new layer changes the perception of the entire research process.

Recommendations Based on Survey Analysis

The findings of the research are clearly implied in seven recommendations developed by the research team. These recommendations were reviewed by the Board of Stop Six Community Services and were used to plan services for the older adults in the health center, which opened its doors in April, 1994. The recommendations went far beyond issues related to the health care facility to be built and the health care personnel that would be needed to staff it. They go to the root of the health problems in the substandard living conditions experienced by the poor and indicate what must be done to improve their quality of life. Thus, what began as an effort to plan for communityoriented primary health care ended with an understanding that the creation on a COPC plan involves many dimensions of community life beyond health care services per se.

<u>Recommendation I.</u> Given that the majority of the older adults reported needing repairs to their homes, a housing program be developed to help meet this need.

Recommendation II. Given the large percentage of older people who rely on the public, family, and friends for transportation, transportation programs must be developed to address that need.

Recommendation III. Given the self-reported poor health of elderly respondents in this survey, the difficulty with activities of daily living and the under-utilization of social services, active outreach programs must be developed to help older people gain access to the services that are available. Where services are not adequate, those services must be expanded.

Recommendation IV. The older adults in this survey appear to have had fewer visits to a doctor in the past year than is usually reported and a substantial number reported difficulty in getting care they needed. Active outreach to encourage older adults to use the new health center should be developed.

Recommendation V. To alleviate the problem of a substantial minority of respondents who reported difficulty purchasing prescription medicines, older adults seen in the health center should be screened for financial eligibility for Medicaid and the need for prescription medicine should be monitored closely so that the elderly patients can obtain the medicines they need in a timely fashion.

<u>Recommendation VI</u>. Given the under-utilization of dental services and the substantial minority of older people who reported difficulty obtaining dental care when needed, active outreach programs must be developed to include older people into the dental services provided by the health center.

Recommendation VII. Given the substantial percentages of the older adults who report problems with loneliness, anxiety, and depression, and the under-utilization of mental health services, the health center should screen older adults for serious mental health problems and refer those needing professional services to appropriate mental health professionals. In addition, more active outreach programs should be developed to involve older people in existing services for seniors, such as the senior center and meal programs.

Lessons Learned in Using PAR with Community Groups

From this experience, the university-based researchers and the community members learned valuable lessons that can be useful to other communities and researchers who choose to collaborate on projects that use the PAR model for health care research or for other projects important to community sustainability. The most important lessons are

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- 1. Be patient. PAR takes time.
- 2. PAR involves cooperation, not control. Learn the art of compromise.
- 3. Invite and structure multiple opportunities for input from all relevant parties at each step in the research.
- 4. Everyone wants something; work toward everyone getting something.
- 5. Everyone has something to offer. Take time to learn what it is and use it to advantage in the research.
- 6. Not everyone knows what you have to offer. Take time to educate them.

- 7. Trust takes a long time to develop but is quickly destroyed. Be scrupulously honest.
- 8. Some differing points of view can be resolved, some cannot. Learn to accept, adapt, agree to disagree and move on.
- 9. Research is a process, not a product.
- 10. Never give up. Tomorrow is another day.

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Mrs. Walter Beatrice Barbour was member of the Stop Six Community Board whose leadership contributed greatly to the project reported in Susan Eve's article (pp.) Born and raised in Fort Worth, Mrs. Barbour earned a bachelor's degree from Prairie View A&M, and a masters degree from Atlanta University. Certified in counseling and human relations, she worked as a teacher and a guidance counselor in Fort Worth schools. Her leadership style emphasizes working together with all sectors of the community—all race and ethnic groups, all socio-economic groups, the public and the private sector—to create a stronger community for all. Her philosophy of leadership was reflected in many of the board's actions and it could be useful in other community settings.

ON LEADERSHIP By Walter Beatrice Barbour

What is leadership?

Its qualities are difficult to define. But they are not so difficult to identify.

Leaders don't force other people to go along with them. They bring them along. Leaders get commitment from others by giving it themselves, by building an environment that engages creativity, and by operating with honesty and fairness.

Leaders demand much of others, but also give much of themselves. They are ambitious—not only for themselves but also for those who work with them. They seek to attract, retain and develop other people to their full abilities

Good leaders aren't "lone rangers" They recognize that an organization's strategies for success require the combined talents and efforts of many people. Leadership is the catalyst for transforming those talents into results.

Leaders know that when there are two opinions on an issue, one is not bound to be wrong. They recognize that hustle and rush are the allies of superficiality. They are open to new ideas, but they explore their ramifications thoroughly.

Successful leaders are emotionally and intellectually oriented to the future—not wedded to the past. They have a hunger to take responsibility, to innovate, and to initiate. They are not content with merely taking care of what's already there. They want to move forward to create something new.

Leaders provide answers as well as direction, offer strength as well as dedication, and speak from experience as well as understanding of the problems they face and the people with whom they work.

Leaders are flexible rather than dogmatic. They believe in unity rather than conformity. They strive to achieve consensus out of conflict. Leadership is all about getting people consistently to give their best, helping them to grow to their fullest potential, and motivating them to work toward a common good. Leaders make the right things happen when they're supposed to.

A good leader, an effective leader, is one who has respect. Respect is something you have to have in order to get A leader who has respect for other people at all levels of an organization, for the work they do, for their abilities, aspirations, and needs, will find that respect is returned. And all concerned will be motivated to work together.

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