

Reducing Diabetes Health Disparities through Community-Based Participatory Action Research: The Chicago Southeast Diabetes Community Action Coalition

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SYNOPSIS

To address disproportionately high rates of diabetes morbidity and mortality in some of Chicago's medically underserved minority neighborhoods, a group of community residents, medical and social service providers, and a local university founded the Chicago Southeast Diabetes Community Action Coalition, a Centers for Disease Control and Prevention REACH 2010 Initiative. A community-based participatory action research model guided coalition activities from conceptualization through implementation. Capacity building activities included training on: diabetes, coalition building, research methods, and action planning. Other activities sought to increase coalition members' understanding of the social causes and potential solutions for health disparities related to diabetes. Trained coalition members conducted epidemiologic analyses, focus groups, a telephone survey, and a community inventory. All coalition members participated in decisions. The participatory process led to increased awareness of the complexities of diabetes in the community and to a state of readiness for social action. Data documented disparities in diabetes. The participatory action research approach (a) encouraged key stakeholders outside of the health care sector to participate (e.g., business sector, church groups); (b) permitted an examination of the sociopolitical context affecting the health of the community; (c) provided an opportunity to focus on preventing the onset of diabetes and its complications; (d) increased understanding of the importance of community research in catalyzing social action aimed at community and systems change and change among change agents.

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The Midwest Latino Health Research, Training, and Policy Center (the Latino Health Research Center), a unit of the Jane Addams College of Social Work at the University of Illinois at Chicago, was founded in 1993 for the purpose of engaging in outcomes research, training, and policy change in the area of health disparities. The Latino Health Research Center has followed community participatory action research (PAR) approaches since its inception. In 1999, the Center received funding from the Racial and Ethnic Approaches to Community Health (REACH) 2010 program of the Centers for Disease Control and Prevention (CDC) to reduce diabetes disparities. REACH 2010 is a two-phase demonstration project that calls for coalition building aimed at community mobilization to reduce health disparities. REACH 2010 seeks to address health disparities related to cardiovascular disease; cancer, particularly breast and cervical cancer; diabetes; HIV/AIDS; child and adult vaccinations; and infant mortality.

The REACH 2010 Phase I Initiative called for (a) a lead agency/partner as the central coordinating organization; (b) partnership with a local or state health department; and (c) partnership with an academic institution. During the 12-month Phase I period, these partners, working with community residents and local organizations, were expected to establish a coalition for the purpose of conducting a comprehensive community assessment that would result in an action plan to be implemented during Phase II.

While preparing the CDC REACH 2010 grant application, the Latino Health Research Center invited individuals, community organizations, and local health and human service providers to a series of town meetings to assess which health disparities and which communities had the greatest need for a multipronged research and action approach. After several meetings, community leaders recommended a strategy that included forming a coalition of African American and Latino organizations in Chicago's racially diverse Southeast Side. The rationale for an African American and Latino coalition was based on an understanding that there are more similarities than differences between Latinos and African Americans in the U.S. and on the Southeast Side: these are the largest minority groups; both groups are characterized by low levels of education and income and high levels of poverty; and both groups are affected by disparities in health and access to health care. Members of both groups tend to have a strong sense of family, community, and religiosity/spirituality, and many members of both groups use home remedies and over-the-counter medications to

treat symptoms of illnesses. The rapid growth of the Latino population, the widespread gentrification of Chicago's neighborhoods, and the demolition of public housing have forced these groups to live in the same communities. A secondary goal of the project was to bring these groups together around common issues like diabetes. If successful in meeting these goals, the coalition would have developed a model of improving race relationships for other communities to follow nationwide.

The community leaders recommended targeting the Southeast Side of Chicago because the area experiences what Doug Gills refers to as a "convergence of disadvantage"¹—low socioeconomic status,² disinvestments,² and documented health disparities.³

Chicago's Southeast Side includes six community areas (CAs): South Shore (CA43), South Chicago (CA46), Calumet Heights (CA48), South Deering (CA51), East Side (CA52), and Hegewisch (CA55). Historically, these CAs were collectively called the "Calumet Area Steel Belt of the Midwest" because the major sources of employment were steel mills, railroad cart production facilities, and the automotive industry. During the 1970s, the steel industry declined almost to extinction. By the 1980s, severe unemployment and displacement were apparent throughout the region.² The Chicago Southeast community areas have never recovered from this devastation.

Local organizations have a history of community organizing around social justice issues and had previous experience in using PAR in addressing health concerns, especially in the areas of HIV/AIDS, maternal and child health, asthma, and breast cancer. However, diabetes control and prevention were not prominent on the local agenda. Based on available diabetes-related data^{4,5} and further consultation with key partners, it was determined that these communities could be mobilized around diabetes and reach a state-of-readiness,⁶ that is, engage in targeted actions to reduce diabetes-related mortality and complications, with ancillary efforts pointed toward increasing adult vaccination for influenza, for which people with diabetes are at elevated risk.⁷

In July 1999, the founding members of the Chicago Southeast Diabetes Community Action Coalition (CSEDCAC) submitted a REACH 2010 Phase I proposal. In addition to the Latino Health Research Center, the principal partners were the Southside Health Consortium, a network of community hospitals and primary care facilities (now known as the Healthcare Consortium of Illinois); the Illinois Diabetes Control Program of the Illinois Department of Human Ser-

vices; and *Centro Comunitario Juan Diego*, a local community organization that primarily serves recent immigrants. See Figure 1 for a list of coalition members.

A number of factors played into the decision to focus on diabetes: high diabetes mortality in the target communities; high diabetes-related hospitalization rates, based on hospital discharge data; and high gestational diabetes rates.^{4,5} The present article describes (a) the PAR theoretical approach developed by the Latino Health Research Center and practiced by CSEDCAC from its inception⁸; (b) selected research findings from REACH 2010 Phase I activities; and (c) current and planned coalition activities.

THEORETICAL FRAMEWORK

PAR refers to a family of methodologies that can be used to pursue research objectives (knowledge, understanding) with the meaningful involvement of community members (stakeholders) and an ultimate focus on social action leading to improvements in social

conditions.⁹ PAR approaches focus on building community capacity through training, which leads to consciousness raising and a state of readiness for action. Community leaders and stakeholders develop the knowledge and skills to take action aimed at changing community conditions and systems so that a supportive environment (context) exists to sustain behavior changes over time.⁹ Examples of capacity building include facilitating the development of community infrastructures such as coalitions and providing training aimed at assisting communities in understanding the social and political context of problems and their potential solutions.

Action research has links to and is informed by a number of intellectual traditions, although it is not defined by any one of them. The seminal work of Kurt Lewin,¹⁰ Carr and Kemmis,¹¹ and Reason and Rowan¹² are usually acknowledged. Action research has much in common, however, with a range of other traditions, including practitioner research, action inquiry, action science, and community development. Its intellectual

Figure 1. CSEDCAC member organizations

MEMBER	SECTOR
Advocate Trinity Hospital	Provider
African American Dietetics Association	Provider/professional organization
Black Nurses Association	Provider/professional organization
<i>Centro Comunitario Juan Diego</i>	Community-based organization
Chicago Family Health Center	Provider
Chicago Park District	Government/recreation
Guadalupe Senior Center	Community based organization
Healthcare Consortium of Illinois	Community-based organization
Healthy South Chicago	Community-based organization/consumers
Hispanic American Foundation for the Advise ment of Health	Provider/professional organization
Illinois Diabetes Control Program, Illinois Department of Human Services	Government
Illinois Hispanic Nurses Association	Provider/professional organization
Jewel-Osco Drug	Business
Jackson Park Hospital	Provider
Latinos for a Healthy Illinois	Community-based organization/advocacy
Midwest Hispanic Health Coalition	Community-based organization/advocacy
Midwest Latino Health Research, Training, and Policy Center, Jane Addams College of Social Work, University of Illinois at Chicago	Research
Neighborhood Block Clubs	Community-based organizations
Network of Churches	Religious
Office of Minority Health, U.S. Department of Health and Human Services Region V	Government
People Living with Diabetes	Consumers
South Chicago Chamber of Commerce	Business
South Shore Hospital	Provider
Tellez Medical Center	Provider
We Care Dental	Provider

roots are likewise diverse; action research has been linked to Moreno,¹³ Freire¹⁴ and the communication theory associated with Habermas¹⁵ and the Frankfurt school.

Fundamental to our understanding of community-based PAR is that it must be viewed as a philosophy, a process, and an outcome.¹⁶ PAR activities are flexible, aimed at understanding and solving important community problems, and involve community participation and ownership throughout the entire research project, particularly from those directly impacted by the problem. Typically, PAR approaches employ a diverse set of data collection strategies, both quantitative and qualitative, and broadly define the role of the researcher. In keeping with the goal of capacity building, PAR provides resources to communities, including jobs, technical assistance, and training, as well as other community benefits. (But, most important, PAR stresses targeted action at various strategic points during a project and, once the research has been completed, the use of research results to engage in social action and policy development. (See Figure 2.)

In addition, three issues common to all participatory efforts must be fully addressed throughout each project: a “level playing field” among coalition members; a governance structure that is truly participatory; and a clear goal of engaging in community capacity-building.

1. There must be a “level playing field” among coalition members.¹⁷ The inherent inequality between academic researchers, health care providers, and community organizations has to be recognized, and action must be taken to ensure that *to the extent possible* these structural inequities are remedied in the context of the partnership and the work at hand. Key to ensuring a level playing field is negotiating financial matters up front and sticking to those agreements through formal mechanisms, e.g., letters of agreement. In the case of CSEDCAC, financial arrangements were negotiated as part of the grant writing process; to allow for new partners to be added as needed, a certain amount of flexibility was built into the arrangements. Adjustments for level of effort and changes in the division of work can be made on an annual basis.

Figure 2. Differences between traditional/mainstream research and participatory action research

TRADITIONAL/MAINSTREAM RESEARCH	PARTICIPATORY ACTION RESEARCH
Rigid	Flexible
Has limited or no utility in understanding or solving important community problems.	Aimed at understanding and solving important community problems.
Seeks limited community representation when funding has been obtained.	Seeks community participation at the initiation of the project.
Uses mainly quantitative methods.	Uses both qualitative and quantitative methods.
Tends to include women and members of ethnic minority groups as study participants.	Maximizes efforts to include groups affected by the problems.
Stresses cultural deficits and a “victim” ideology.	Stresses community assets and individual and community empowerment.
Research is “on” minorities or other “populations.”	Research is “with” and “by” minority group members/ community participants.
Principal investigators are in control.	Shared governance/ownership; participants have leadership roles.
Project ends when data are collected and analyzed.	Real action starts when data are analyzed.
“Partnership” is limited.	Shares resources, provides jobs, technical assistance, and training.
Researcher is the “expert.”	Researcher is a resource person who facilitates and educates.

2. At all stages of work, the governance structure must be fully participatory.¹⁸ Without open communication and shared decision-making, trust and commitment among members will waiver and endanger completion of the work. Further, in a successful coalition, each member brings different strengths and full participation improves the quality of decisions.¹⁹ CSEDCAC accomplished this by developing a decision-making framework that was fully discussed and agreed upon among coalition members. The decision-making framework delineates ultimate responsibility for decisions related to membership, vision, goals, and objectives; conflict resolution; coalition sustainability; and planning and evaluation.

Participatory processes take place at monthly open meetings held in public places (most often the local library) and through meeting agendas and minutes, guest speakers, and training opportunities related to diabetes self-management. Anyone who attends the monthly meeting is invited to join a working committee (task force), formed to focus on specific community needs assessment tasks (e.g., focus groups, telephone survey); to sign up for the mailing list; and to receive periodic e-mail updates and bilingual newsletters. New participants are invited to a coalition orientation session, which is held at the same time as the task force meetings. Diabetes screening, flu shots, and foot examination for people with diabetes are also available during monthly coalition meetings. In addition, guest speakers are invited to address diabetes-related issues as a means of keeping the membership informed of up-to-date diabetes information.

3. A key goal is building community capacity.^{1,18} While the inherent structural inequities between research institutions and their partners will not be remedied in the context of any single participatory research project, continued efforts at building the capacity of the community to meet its own needs lessens the operational impact of inequalities and allows, over time, for community partners to take stronger and more directive roles in the research process.

During CSEDCAC Phase I activities, community capacity building included training for community agency staff and concerned citizens on diabetes, coalition building, and research methods.

LATINO HEALTH RESEARCH CENTER PAR MODEL

The PAR model developed by the Latino Health Research Center has been applied to a diverse set of health issues—including environmental exposure, diabetes prevention and control, cancer prevention and control, and tobacco control⁸—and has been refined

over the years. Figure 3 summarizes the major steps in the participatory process and highlights some of the activities necessary to progress from step to step.

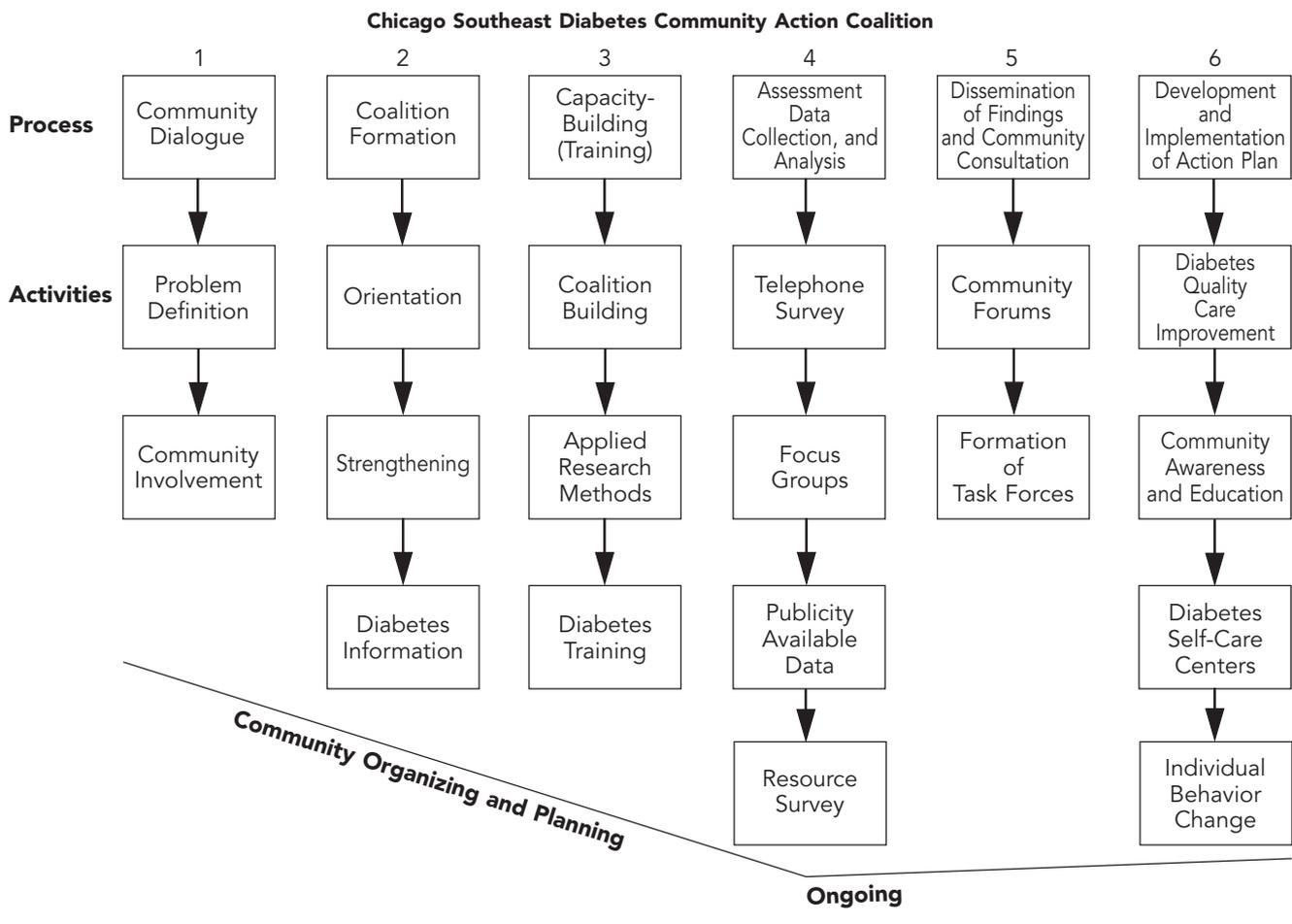
COMMUNITY DIALOGUE

Once the community areas were selected, the Latino Health Research Center initiated a dialogue with local leaders to explain the REACH 2010 Initiative and explore their interest in becoming partners. The Southside Health Consortium facilitated this process and was instrumental in bringing key community leaders to the table. About 15 community representatives agreed to become partners and began working closely with the Latino Health Research Center to provide the data necessary to document community needs with regard to the impact of diabetes on community members and the local health care delivery system. The community representatives worked closely to develop the grant application, including the budget. This approach allowed the principal partners to tailor the proposal to the specific concerns community leaders had raised about diabetes-related issues, thereby increasing community buy-in and strengthening the chances that the project, if funded, would be successful. During this period, the Illinois Diabetes Control Program, a long-time Latino Health Research Center partner in diabetes prevention and control efforts, became involved. The Illinois Diabetes Control Program suggested to the group that influenza vaccinations for people with diabetes should be the second focus of the REACH 2010 application.

COALITION FORMATION

The Latino Health Research Center's experience has shown that developing group trust must be attended to early in the organization of a coalition. In the Latino Health Research Center's practice, group trust and cohesiveness is facilitated through a series of group exercises allowing partners to get to know each other not only at a professional level but also at a personal level. Sharing stories about personal interest in diabetes (e.g., diabetes in the family or living with diabetes) facilitates the process. The group activities provide a way for partners to develop a style of working together. This allows partners to make informed decisions regarding participation and to commit to coalition activities.

When CSEDCAC was formed to apply for REACH 2010 Phase I funding, coalition members adopted a mission statement and principles of collaboration (see Figure 4). The mission, goals, objectives, and principles were reaffirmed in January 2002 during a coali-

Figure 3. Participatory research and coalition-building model

tion retreat, held at the outset of REACH 2010 Phase II activities.

Once Phase I funding was obtained in September 1999, memoranda of agreement were revised with the community partners, specifying roles and responsibilities; project staff was hired and trained; and the coalition's organizational structure was formalized. The organizational structure consists of a steering committee, a core group including representatives of the REACH 2010 project central coordinating organization (the Latino Health Research Center), co-principal investigators from the Southside Health Consortium and the Illinois Diabetes Control Program, and conveners of the task forces.

Phase I task forces planned and implemented: (a) focus groups for health care providers; (b) focus groups for people with diabetes and people at risk of developing diabetes; (c) a community inventory; (d) a compilation of epidemiologic data; and (e) a telephone survey. For Phase II, the coalition reorganized to implement the action plan developed during Phase I.

During Phase II, task forces were reorganized into committees to conduct work in the areas of: (a) community awareness education; (b) quality improvement; (c) diabetes self-management and control programs; (d) policy; and (e) evaluation. Task forces and committees play a vital role; much of the actual work of the coalition is delegated and conducted through them; they have been invested with decision-making power.

Capacity building through training

During Phase I, CSEDCAC engaged in building community capacity by training community agency staff, local providers, and community residents, including people with diabetes. Task force members received training in the methods for which they were providing leadership. Training sessions were offered in Spanish and English. Topics included: (a) diabetes and its complications; (b) clinical guidelines; (c) employing diabetes as a community organizing tool through use of Diabetes 101, a brief version of *Diabetes Today*, a bilingual curriculum developed by ROW, Inc., under CDC

Figure 4. Mission Statement, Central Goal, Objectives, and Principles of Collaboration of the Chicago Southeast Diabetes Community Action Coalition (CSEDCAC)

Mission Statement:

Assure and enhance access to quality health services and quality of life of persons at risk for and with diabetes in Chicago Southeast communities through the establishment and institutionalization of a diabetes coalition of community residents, health and human services providers, and persons living with diabetes or at risk for developing diabetes.

Central Goal:

To reduce diabetes mortality, hospitalizations, complications, and related disabilities among African Americans and Latinos in Chicago's Southeast Side communities.

Objectives:

- Mobilize communities through the establishment of CSEDCAC.
- Empower communities through participatory research by conducting a comprehensive assessment of diabetes-related issues.
- Develop and implement a diabetes Community Action Plan.
- Integrate and expand diabetes care as a health priority area.

Principles of Collaboration:

- Commitment to equity, collective decisions, and collective action.
 - High quality, ethical research and interventions.
 - Joint ownership of data.
 - Collective interpretation and dissemination of results.
 - Welfare of coalition members—that is, no partner shall act in any manner that is considered detrimental to another partner.
 - Institutionalize programs that benefit the community through pursuing new funding.
 - Challenge social and environmental inequalities that affect health.
 - Support diabetes-related community changes and actions that ultimately will lead to positive health outcomes.
-

sponsorship, which stresses community mobilization as a strategy for diabetes control and prevention; (d) coalition-building strategies; (e) applied research methods; (f) accessing publicly available data; (g) performing a community-wide resource survey; and (h) action planning.

Data collection

Specific objectives were developed for Phase I activities:

- Identify key social, medical, environmental, cultural, institutional, and behavioral factors that may be associated with racial/ethnic disparities in diabetes risk, prevalence, and quality of care among Latinos and African Americans and other groups in specific community areas on Chicago's Southeast Side.
- Identify effective strategies for diabetes prevention and control through community action planning.

- Engage in analysis and dissemination so as to allow replication and adaptation of the project to other communities.

The task forces developed detailed work plans with deadlines and identified specific coalition members who would provide leadership for each activity. Each task force developed and revised the study instruments needed for their work (including consent forms), thus allowing full discussion of the cultural appropriateness of all documents. The methods for reaching the target population for the telephone survey and focus groups were determined by the appropriate task forces, as were specific research procedures and data collection protocols.

Focus groups

The members of the focus group task force were trained in focus group procedures, including planning, recruiting participants, developing screening tools and question guides, and focus group logistics. Individuals who

wished to serve as facilitators were trained in group facilitation. The question guides were pilot-tested with English and Spanish-speaking individuals.

A total of 14 focus groups were held: two with local health care providers, including family physicians, pediatricians, registered nurses, nutritionists, and social workers; six with local residents living with diabetes, one of which was conducted in Spanish for recent immigrants; and six with people determined to be at risk for developing diabetes, using the criteria set by the American Diabetes Association.²⁰ In total, 128 individuals participated in the focus groups. Along with an informed consent document, participants were asked to complete a self-administered questionnaire at the beginning of the session.

Tapes of the group meetings were transcribed and then reviewed for accuracy by coalition members and project staff. Coding categories were then used to develop the major themes embedded in the data. These themes were then analyzed for each ethnic group. Discrepancies were reviewed by task force members until a consensus was reached.

Telephone survey

The specific aim of the telephone survey was to obtain quantitative data on key access, medical, environmental, and behavioral factors that may be associated with racial/ethnic disparities in diabetes risk, prevalence, and quality of care. The telephone survey questionnaire was built upon CDC's Behavior Risk Factor Surveillance System (BRFSS) and was designed to obtain data compatible with state and national datasets. Members of the telephone survey task force were trained in survey methodology and sampling techniques. They also assisted with identifying and training community residents to conduct the telephone interviews, pilot testing the survey, supervising interviewers, and maintaining quality control during data collection.

The telephone survey was based on a probability sample using random digit dialing in pre-selected ZIP Code areas (60617, 60633, 60649). Respondents were ≥ 18 years of age. In households with more than one eligible member, the one with the most recent birthday was selected. A total of 411 interviews were completed. Of these, 394 were included in the analysis; individuals who did not self-identify as non-Hispanic black, Hispanic/Latino, or non-Hispanic white were excluded. SPSS was used for these analyses.²¹

Community inventory

Task force members, along with CSEDCAC project staff, conducted a community inventory of health and human services to determine gaps in service. The task

force developed a community inventory form that allowed data to be entered and sorted by ZIP Code, category, and services available. Several data collection approaches were used, including reviewing local social services directories and conducting field observations in the project's community areas. A total of 450 organizations were identified.

Epidemiology

This task force focused its efforts on collecting publicly available data. Data sources included the U.S. Census Bureau; the Illinois Center for Health Statistics and the Bureau of Vital Statistics of the Illinois Department of Public Health; the Illinois Foundation for Quality Health Care; and the CDC and the Illinois Department of Public Health for BRFSS data.

RESEARCH FINDINGS

Selected health indicators, utilization of diabetes services, and hospitalizations

The epidemiological and survey data provided evidence that the target communities experienced high mortality for heart disease, cancer, stroke, and diabetes.⁵ For example, our epidemiological analyses indicated that diabetes mortality in the target communities varied from 13 per 100,000 in CA52 (Hegewisch), a neighborhood with a largely non-Hispanic white population, to 40 per 100,000 in CA51, South Deering, in 1995–1997. This compares to a diabetes mortality rate of 18 per 100,000 for the city of Chicago as a whole.⁵

In 1999–2000, coalition health care facilities saw a total of 5,573 outpatients with diabetes. Over the two-year period, 5,603 unduplicated individuals were seen as inpatients with diabetes as a primary or secondary diagnosis. This may indicate a high level of complications among people with diabetes in the area, an indication that their diabetes may have been poorly controlled. Vast majorities of the diabetes clients (outpatient and inpatient) were non-Hispanic black, older than 45, and female, according to partners' medical databases. The high cost of diabetes hospitalization is also reflected in 1994–1998 hospital discharge data for the CSEDCAC communities, tabulated by ZIP Code (60617, 60628, 60633, 60649) (Unpublished data, Illinois Foundation for Quality Health Care). The local population of 166,550 accounted for 5.7% of all Chicagoans.^{22,23}

Telephone survey results

A total of 394 survey responses were analyzed, representing 273 respondents who self-identified as non-Hispanic black, 52 as non-Hispanic white, and 69 as

Hispanic/Latino (Table 1). Most respondents were female (69.9%). Respondents had a mean age of 44.5 years; non-Hispanic white respondents had the highest mean age (51.2 years), and the Hispanic/Latino group the lowest (38.3 years mean age). Respondents had a mean of 12.7 years of education; Hispanics had the lowest level of education (mean of 9.8 years).

The sample population appeared to be of low socioeconomic status based on the high unemployment rate (20.4%), which reached 42.6% among Hispanics/Latinos; a high level of participation in government benefit programs (27.6%), particularly among non-Hispanic black (27.7%) and Hispanic/Latino respondents (33.3%); and worry concerning food insufficiency (9.1%), which was particularly high among Hispanic/Latino respondents (13.0%).

Access to care. Access appeared to be problematic, particularly for Hispanic/Latino respondents, who reported a variety of financial and linguistic barriers. Approximately 21% of Hispanic/Latino respondents reported no health insurance; 23.9% reported linguistic barriers in communicating with their health care providers. When considered together, these two factors may explain the reportedly lower frequency of selected preventive services, including regular physical exams, blood pressure testing, and cholesterol screening (Table 1).

Prevalence of diabetes. Based on the telephone survey findings, the prevalence of diabetes in the total target population (ages ≥ 18 years) was estimated to be 16.3%. The self-reported prevalence was highest among non-Hispanic white respondents (22%), followed by non-Hispanic blacks (16.6%) and Hispanics/Latinos (10.8%). The percentage of women who reported a history of gestational diabetes was 12.1%; the percentage was particularly high for Hispanic/Latina (17.6%) respondents, compared to those for non-Hispanic white (11%) and non-Hispanic black (10.7%) respondents.

Other health status indicators. Non-Hispanic white respondents reported the highest prevalence of certain conditions, such as heart disease (14%) and high cholesterol (26%), while the reported prevalence of kidney disease was highest among Hispanic (9%) and non-Hispanic black respondents (3.7%). The prevalence of high blood pressure was the highest among non-Hispanic black respondents (29.7%).

Data on a number of health indicators suggested that the entire Southeast Chicago community, regardless of ethnicity, was at risk for diabetes. For example, more than half of the respondents reported one or more relatives with diabetes. An average of one in 10 women reported having given birth to a baby who

weighed more than 9 pounds. Elevated diabetes risk was also reflected in the prevalence of overweight (22.3%) and obesity (25.2%) based on Body Mass Index (BMI); in the number of times respondents reported eating at fast food restaurants (3.2 times per week); and in the percentage of people (73.4%) who reported eating outside their homes on a regular basis.

The telephone survey obtained additional information from respondents diagnosed with diabetes (Table 2). Findings indicated that the mean age of people with diabetes was 56 years, compared to a mean age of 44 for the total sample (Table 1). Their socioeconomic status appeared to be worse than that of the entire telephone sample (Table 1) based on the percentages of people unable to work due to diabetes, rates of unemployment, percentages of people depending on government benefit programs, and percentages of people with diabetes who reported being worried about not having enough food. Furthermore, about 30.5% of people with diabetes reported that their health was fair, compared with 21.4% for the total survey sample. The poorer health status was particularly true for the minority groups in the target communities. Latino respondents with diabetes reportedly experienced greater financial barriers in accessing services due to their lack of health insurance; approximately 43% of Latino, 9% of non-Hispanic white, and 12% of non-Hispanic black respondents with diabetes reported not having insurance coverage. Prevalences of overweight and obesity were much higher among people with diabetes than among the total telephone sample. About 37.5% of respondents with diabetes were obese based on the BMI. High percentages of respondents with diabetes reported having relatives with diabetes (80.0%), having given birth to a large baby (16.7%), having a history of gestational diabetes (36.8%), having one or more chronic conditions in addition to diabetes (70.0%), and having hypertension (59.3%).

Quality of care. Measures of quality of diabetes care were based on recommendations of the Illinois Diabetes Control Program.²⁴ We found that only 51.7% of respondents with self-reported diabetes said they had ever received formal diabetes education. The percentage was higher for non-Hispanic white respondents (63.6%) than for Hispanic/Latino (57.1%) or non-Hispanic black (47.5%) respondents. Approximately 19% of those with diabetes said they did not know what type of diabetes they had, including 42.9% of Hispanic/Latino respondents with diabetes, 17.5% of non-Hispanic black respondents with diabetes, and 9.1% of non-Hispanic white respondents with diabetes. Only 84.5% of individuals with diabetes reported having had a dilated eye exam during the past year.

Table 1. Selected health disparities indicators for telephone survey respondents

Self-reported characteristic	Self-reported race/ethnicity			Total (N=394)
	Non-Hispanic black (n=273)	Non-Hispanic white (n=52)	Hispanic/ Latino (n=69)	
Demographics				
Sex				
Male	31.1	30.8	24.6	30.1
Female	68.9	69.2	75.4	69.9
Age				
18–44	51.3	36.6	72.5	53.7
45–64	30.9	34.6	18.8	29.0
≥65	17.8	28.8	8.7	17.3
Mean age (years)	44.7	51.2	38.3	44.5
Mean years of education	13.5	12.5	9.8	12.7
Socioeconomic status				
Percent unemployed	15.1	19.2	42.6	20.4
Percent participating in government benefit programs ^a	27.7	19.2	33.3	27.6
Percent worried about not having enough food within past 30 days	9.1	3.9	13.0	9.1
Access to medical care				
Percent without a regular source of health care	6.2	0.0	7.2	5.9
Percent needed medical care but did not get it within past year	8.1	5.8	13.0	8.7
Percent without health insurance	12.8	1.9	20.6	13.3
Percent with difficulty communicating with providers because of language barrier	—	—	23.9	23.9
Health status				
Percent of people ages ≥18 years with diabetes	16.6	22.0	10.8	16.3
Percent with health status perceived as fair	19.9	17.3	33.3	21.4
Percent with two or more years without physical exam	10.3	21.6	25.0	14.4
Percent with two or more years without blood sugar test	20.6	18.0	28.5	21.6
Percent with two or more years since blood pressure tested	5.1	9.8	13.5	7.2
Percent with two or more years since blood cholesterol tested	25.7	28.3	39.1	28.4
Percent with flu shot within past year	28.6	44.2	24.6	29.7
Prevalence of chronic conditions (percent of respondents)				
Heart disease	7.8	14.0	7.5	8.5
High cholesterol	15.9	26.0	17.9	17.6
Kidney disease	3.7	—	9.0	4.1
High blood pressure/hypertension	29.7	22.0	19.4	26.9
One or more chronic conditions	37.0	40.4	36.2	37.8
Diabetes risk factors				
Percent with one or more family member with diabetes	53.1	48.1	56.5	53.0
Percent of women who gave birth to a baby weighing >9 pounds	8.9	12.5	13.0	10.3
Percent women who ever had gestational diabetes	10.7	11.1	17.6	12.1
Lifestyle risk factors				
Percent overweight (BMI >27)	21.8	29.2	19.4	22.3
Percent obese (BMI >30)	26.0	20.8	25.4	25.2
Mean times eating outside home weekly	3.4	3.4	2.4	3.2
Percent ate foods not prepared at home within past week	73.4	75.0	73.5	73.7
Percent smoked five or more packs of cigarettes in lifetime	38.9	58.8	35.8	41.5

^aTANF, Medicaid, SSI, Social Security retirement or disability benefits, WIC, Food Stamps, public housing, and various meal programs.

Table 2. Selected health disparities indicators for telephone survey respondents with self-reported diabetes

Self-reported characteristic	Self-reported race/ethnicity			Total (N=60)
	Non-Hispanic black (n=42)	Non-Hispanic white (n=11)	Hispanic/ Latino (n=7)	
Demographics				
Mean age (years)	55.8	60.5	50.7	56.1
Mean years of education	12.9	12.2	9.3	12.4
Socioeconomic status				
Percent unable to work because of diabetes	17.5	9.1	42.9	19.0
Percent unemployed	9.5	36.4	28.6	16.7
Percent participating in government benefit programs ^a	29.3	27.3	42.9	30.5
Percent worried about not having enough food	20.0	0	28.6	17.2
Access to medical care				
Percent without a regular source of health care	4.8	0	0	3.3
Percent needed medical care but did not get it within past year	14.3	9.1	14.3	13.3
Percent without health insurance	11.9	9.1	42.9	15.0
Percent with difficulty communicating with providers because of language barrier	—	—	0	0
Health status				
Mean age when told they had diabetes	44.9	47.8	38.4	44.6
Individuals with self-reported diabetes as percent of telephone survey sample (N=394)	16.3	22.0	10.8	16.1
Perceived health				
Percent excellent/very good/good	48.7	73.0	42.9	52.6
Percent fair	34.1	9.1	42.9	30.5
Percent poor	17.1	18.2	14.3	16.9
Self care/quality of care				
Percent did not know their of type of diabetes	17.5	9.1	42.9	19.0
Mean number of HbAc1 within past year	2.9	3.0	1.7	2.8
Mean number of times health provider checked feet within past year	3.8	3.4	1.5	3.6
Percent had a dilated eye exam within past year	85.0	90.9	71.4	84.5
Percent ever received diabetes education classes	47.5	63.6	57.1	51.7
Percent saw a dietitian or nutritionist within past year	32.5	27.3	42.9	32.8
Percent had a flu shot within past year	45.2	72.7	42.9	50.0
Percent taking aspirin every day or every other day	31.0	27.3	14.3	28.3
Percent had physical exam within past year	90.4	100.0	71.4	89.8
Percent check feet daily	87.5	81.8	100.0	87.9
Percent check blood sugar daily	42.5	54.5	28.6	43.1
Diabetes risk factors				
Percent with one or more family member with diabetes	81.0	63.6	100.0	80.0
Percent of women who gave birth to a baby weighing >9 pounds	11.5	16.7	50.0	16.7
Percent women who ever had gestational diabetes	37.0	42.9	25.0	36.8
Percent with one or more chronic conditions	69.0	72.7	71.4	70.0
Percent with hypertension	64.3	40.0	57.1	59.3
Lifestyle risk factors				
Percent overweight (BMI >27)	35.0	33.3	14.3	32.1
Percent obese (BMI >30)	32.5	33.3	71.4	37.5
Mean times eating outside home weekly	3.0	4.7	2.0	3.2
Percent ate foods not prepared at home within past week	69.0	81.8	71.4	71.7
Percent smoked five or more packs of cigarettes in lifetime	42.5	72.7	71.4	53.3

^aTANF, Medicaid, SSI, Social Security retirement or disability benefits, WIC, Food Stamps, public housing, and various meal programs.

The proportion was highest among non-Hispanic white (90.9%) respondents with diabetes. Approximately 33% of those with self-reported diabetes said they had seen a dietitian within the past year. These respondents also reported an average of 2.8 HbA_{1c} tests in the past year.

Self-care among people with diabetes. Only 43.1% of self-reported diabetics said they checked their blood sugar daily. Approximately 88% reported checking their feet daily, and 28.3% reported taking aspirin daily or every other day to prevent cardiovascular complications. In addition, 7.5% of non-Hispanic black and 14.3% of Hispanic/Latino respondents with diabetes reported using home remedies for diabetes (not shown). The proportion of respondents with diabetes who reported receiving an annual influenza (flu shot) vaccine within the past year was 50%. This was highest for non-Hispanic white (72.7%) respondents with self-reported diabetes, followed by non-Hispanic black (45.2%) and Hispanic/Latino (42.9%) respondents.

Focus group findings

Overall, focus group data reinforced telephone survey findings.

Provider focus groups. Seventeen health care providers, four of whom were physicians (two family practice physicians and two pediatricians), participated in the provider focus groups. The other participants included nurses, nutritionists, and social workers. The majority of focus group professionals (13/17) self-identified as African American. The professional focus groups included approximately the same number of males (47%) and females (53%). The majority of professionals were 45 years of age or older.

Providers acknowledged that due to a shortage of minority health professionals and specialized diabetes care, people with diabetes were often not getting the medical care they needed. In addition, failure to accept Medicare and Medicaid reimbursement by specialists was expressed as a concern.

Providers felt that patients needed healthier diets and daily physical activity in order to maintain health. They mentioned that their clients did not want to hear the word "diet," as they associated it with restrictions on the things they wanted to eat. They reportedly encouraged clients to adapt ethnic food choices but provided few concrete strategies.

Continuity of care was another concern for providers. This was seen as a problem for privately insured patients who changed jobs and thereby health plans, resulting in difficulties and delays in securing appointments and medications. Providers also agreed that

some health professionals were not familiar with clinical guidelines for diabetes management and control and that this resulted in poor diabetes care. Participants made several recommendations, including: (a) cultural competency training for health care professionals, particularly related to diabetes standards of care; (b) increasing the availability of after-hours and weekend care at local health facilities; (c) reducing financial barriers through the implementation of sliding fee scales; (d) increasing diabetes community awareness and education through culturally appropriate messages; (e) increasing the availability of diabetes self-management and control education; (f) working with the local park district to increase physical activity opportunities; and (g) networking with the food industry, including grocery chains, to educate them on their role in diabetes prevention and management and to increase the number of stores that display or offer produce at reasonable prices.

Focus groups of people with diabetes or at risk for diabetes. Twelve focus groups were conducted with a total of 96 community residents living with diabetes or at risk for developing diabetes. Eighty-two self-identified as African American, and 35 as Hispanic/Latino. Participants were identified and recruited by clinicians and local leaders who were members of the coalition. Most participants were female, most were 18–44 years of age, and most had eight years of schooling or less. Only six of 96 participants stated, on the participant profile form, that health issues were a problem in the community. They were most likely to identify gangs and substance abuse, including alcohol, as issues of great community concern.

Most people in these focus groups were familiar with basic diabetes information. Like the providers, they reported financial, cultural, and institutional barriers to access to health care for preventive services as well as for the treatment of illnesses, including diabetes. Many reported problems getting food on the table, and viewed fruits and vegetables as unaffordable. They reported difficulty changing personal lifestyle practices, and complained about the difficulties they faced related to physical activities such as walking, due to neighborhood violence, street crime, and unsafe public parks.

DEVELOPMENT AND IMPLEMENTATION OF THE ACTION PLAN

Once data were collected, the task forces worked together to examine and interpret the findings. Preliminary findings were then shared by members of the task force with the coalition as a whole. At this point,

an action plan was drafted. The coalition decided to plan and conduct two community forums (one in English and one in Spanish) to present the preliminary findings and the draft action plan to the community. From these forums, the action plan was finalized and the grant application for REACH 2010 Phase II was prepared. This action plan included a brief story of the coalition, its vision, mission, collective values, and principles; stated the coalition's broader overall goals and objectives; outlined major areas of work with specific measurable goals and objectives; suggested strategies for targeted action; set deadlines; and determined resources needed to implement the plan.

The action plan targets people living with diabetes or at risk of developing diabetes as well as the larger community and aims to change community norms by working not only with community residents and health and human service providers but also with the school system, businesses (e.g., food industry), and labor unions.

Diabetes is a serious health problem strongly related to lifestyle choices such as eating habits and physical activity and to aspects of the social environment such as preventive health care. To reduce health disparities related to diabetes, it is critical to use PAR to engage the community in the change process and to plan community-level interventions. The intervention strategy must follow an ecological approach that includes interventions aimed at individuals, families, the neighborhood, the local health care delivery system, and other community institutions.²⁵

The use of local data is extremely important. A true picture of a community's needs and assets can not be ascertained without a comprehensive community assessment. In our target communities, publicly available data had been tabulated in ways that were not useful in documenting diabetes-related health disparities or planning interventions. During Phase I, CSEDCAC collated data previously organized by community area, ZIP Code, and census tract. New data were also collected through a telephone survey, 14 focus groups, and a survey of local resources. Focus group participants were self-selected from clinicians, local leaders, and community organizations interested in community-based solutions to diabetes. These data are not generalizable to the target community as a whole. While the telephone survey was based on a probability sample, the low number of Hispanic/Latino participants suggests that home telephone service is not uniform, which impacts the generalizability of the survey's findings.

To plan for system change and change among change agents, PAR was used to involve key stakeholders in the research process during Phase I, which en-

sured that community residents and health and human service providers were not mere advisors to the coalition but worked together to define the problem, to determine what data were needed, to collect and evaluate those data, and then to plan and implement community interventions. The immediate objective was to amass the data necessary to develop the action plan. The action plan recognized that reliable community-wide data were not available and called for directing resources to solving this problem. Specifically, CSEDCAC member institutions are being trained in the use of Steps Electronic Collection Analysis Tool (SECAT), a software program used to track preventive and chronic disease care. Data are reported to a centralized database maintained by the Illinois Foundation for Quality Health Care. Reports are available to participating institutions; additionally, the foundation performs analyses comparing local performance to other locales in Illinois and several other states.

PAR also defines the role of the academic institution (the central coordinating organization in the REACH 2010 structure) as one of technical assistance and support. This fosters community empowerment and capacity building by embedding skills in the community. It also ensures a two-way sharing of information and skills.

Action plan implementation began in January 2002. Additional alliances have been formed with the local chambers of commerce, bilingual media outlets, the Chicago Park District, and other important sectors. During Phase II, CSEDCAC has engaged in specific action planning, implemented interventions, and reorganized its task forces into working committees.

Phase II activities include capacity-building (e.g., development of a centralized diabetes patient tracking information system in hospitals and clinics; sustaining the diabetes coalition; expansion of linkages with health and human service organizations for client referrals and follow-up; and the establishment of Diabetes Self-Care Resource Centers); diabetes quality care improvement; community awareness and education; and a diabetes management and control educational program for people with diabetes or at risk for diabetes. As of this writing, two diabetes self-care centers are operating in the target communities. Community health promoters (trained lay health workers) manage the centers. In addition to regularly scheduled diabetes self-management education programs, nutrition classes, and social support, the Centers provide local residents with assistance on a variety of issues. They provide assistance to clients in navigating the health care system, assistance in accessing medication and devices such as glucose meters, and they

organize health fairs in collaboration with other community agencies. Food insufficiency is also addressed. One of the centers is located at *Centro Comunitario Juan Diego*, which maintains a food pantry; the center also provides interpreter services upon request for clients accessing health and human services. One of the centers is directly managed by the Latino Health Research Center, which also operates a *Dulce Corazon* (Sweet Heart) education program for women. *Dulce Corazon*, funded by the Illinois Department of Public Health, is a health education intervention targeted toward women for the purpose of preventing cardiovascular disease.

EVALUATION ACTIVITIES

A rigorous evaluation plan has been developed to measure progress during Phase II. The participatory process has been followed here, also. At the beginning of Phase II, when the task forces were reorganized into working committees, an evaluation committee was formed. This committee, as well as the coalition's evaluation staff and consultant have worked together to design the evaluation. The various instruments and consent forms have been developed in conjunction with the committee, as has the evaluation process.

The Phase II evaluation has multiple levels. On a quarterly basis, a Coalition Effectiveness Survey is distributed to coalition members during coalition meetings to obtain their levels of satisfaction with a number of areas related to the coalition's work, the process by which the work gets done (e.g., communication, governance), and their levels of participation. In addition, evaluation instruments have been developed to assess all coalition activities, from the training of community leaders and health and human services providers to the diabetes self-management education programs for people with diabetes.

The evaluation assessing the impact of interventions aimed at individuals uses behavioral and clinical outcome data. This is particularly true in reference to the implementation of the diabetes self-management education program and the delivery of diabetes care by health care providers following clinical guidelines. The impact of interventions directed toward local change agents is also being measured. While the true measure of this will come later through the analysis of the SECAT client data, in the interim the coalition is monitoring the participation of local clinicians in various training events and their adoption of standards of care among local health care providers.

Fidelity to intervention, i.e., "Is the coalition doing what it has set out to do?" is also being measured.

Each activity and intervention has its own evaluation component. For instance, during the summer of 2002, the South Chicago Chamber of Commerce conducted a healthy eating awareness campaign in local grocery stores and restaurants; this campaign is being evaluated by assessing participation (e.g., number of grocery stores and restaurants that change stocking practices or menus to increase focus on healthy nutrition); a follow-up survey of participants is planned.

The data from the comprehensive community assessment are being used as baseline data; a telephone survey and focus groups will be repeated later in Phase II. Hospitalization data will be compiled at various points during Phase II. The coalition plans to use the SECAT data to measure progress.

CONCLUSION

Most efforts to prevent or control diabetes have focused on changing individual lifestyle practices. CSEDCAC has used a community-based PAR strategy to conduct a comprehensive community assessment and, during Phase II, to implement an action plan with a rigorous evaluation component. The progress of the coalition has been the result of the participatory approach backed up by a tested PAR methodology. To impact the health quality of life for poor and racial/ethnic minority communities and to address health disparities, it is essential to bring together all sectors directly and indirectly affected to meaningfully involve them in all phases—conceptualization, problem definition, planning, data collection and analysis, dissemination of results, action planning, implementation, and evaluation. The role of the investigator remains one of facilitator, educator, and technical expert in the research enterprise.

CSEDCAC uses PAR as an *approach*, a way to engage the community and to ensure that key stakeholders representing many sectors of the community come together to develop a plan. CSEDCAC also uses PAR as a *strategy* to guide the implementation of the plan; key stakeholders actively participate throughout the implementation phase, and the research process can achieve sustained impact long after the project ends.

Finally, researchers and clinicians need to remember that without system reform, many residents living in communities such as Chicago's Southeast Side can not adopt healthy lifestyle practices; options are simply not available. In communities such as this, health education and increased surveillance without system reform only serve to further frustrate a population that has very few options in general.

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REFERENCES

- Gills DC. Unequal and uneven: critical aspects of community-university partnerships. In: Sullivan M, Kelly JG, editors. Collaborative research: community-university partnership. Washington: American Public Health Association; 2001. p. 3-24.
- Bensman D, Lynch R. Rusted dreams: hard times in a steel community. New York: McGraw Hill; 1987.
- Chicago Department of Public Health, Epidemiology Program. Community Area Health Inventory, 1995-1997. Volume I: Demographics and health profiles. Chicago: Chicago Department of Public Health; 1999.
- Hoyert DL, Kochanek KD, Murphy SL. Deaths: final data for 1997. National Vital Stat Rep 1996;47:19.
- Chicago Department of Public Health, Office of Planning, Policy, and Resource Development. Community Area Health Inventory, 1997. Chicago: Chicago Department of Public Health; 1999.
- Goodman RM, Speers MA, McLeroy K, Fawcett S, Kegler M, Parker E, et al. Identifying and defining the dimensions of community capacity to provide a basis for measurement. Health Ed Behav 1998;25:258-78.
- Smith SA, Poland GA. Immunization and the prevention of influenza and pneumococcal disease in people with diabetes. Diabetes Care 2003;26 Suppl 1:S126-8.
- Giachello AL, Rodriguez G, Sayad JV. From data to social action: a case study of community-university partnership for economic justice. In: Sullivan, M, Kelly JG, editors. Collaborative research: community-university partnership. Washington: American Public Health Association; 2001. p. 169-74.
- Stringer ET. Action research. 2nd ed. Thousand Oaks: Sage Publications; 1999.
- Lewin K. Action research and minority problems. J Soc Issues 1946;2:346.
- Carr W, Kemmis S. Becoming critical: education, knowledge, and action research. Philadelphia: Falmer; 1986.
- Reason P, Rowan J. Human inquiry: a sourcebook of new paradigm research. Chichester (UK): John Wiley; 1981.
- Moreno J. Sociometry and the science of man. New York: Beacon House; 1956.
- Freire P. Pedagogy of the oppressed [translated by M. B. Ramos]. New York: Seabury Press; 1974.
- Habermas J. Communication and the evolution of society [translated by T. McCarthy]. Boston: Beacon Press; 1979.
- Fals-Borda O, Rahman MA. Action and knowledge: breaking the monopoly with participatory action research. New York: Apex Press; 1991.
- Peterman W. Neighborhood planning and community development: the potential and limits of grassroots action. Thousand Oaks (CA): Sage; 2000.
- Nyden P, Figert A, Shibley M, Burrows D. Building community: social science in action. Thousand Oaks (CA): Pine Forge Press; 1997.
- Amuwo SA, Jenkins E. True partnership evolves over time. In: Sullivan M, Kelly JG, editors. Collaborative research: community-university partnership. Washington: American Public Health Association; 2001. p. 25-44.
- American Diabetes Association. Diabetes care: standard of medical care for patients with diabetes mellitus. Diabetes Care 2003 Jan;26 Suppl 1:S33-50.
- SPSS, Inc. SPSS 10.1. Chicago: SPSS, Inc.; 1988-2000.
- Northern Illinois Planning Council. Census 2000: summary tables of social, economic, and housing data for the 77 Community Areas in the city of Chicago. Chicago: Northern Illinois Planning Council; 2002.
- Census Bureau (US). 2000 Census of Population and Housing: summary file 3. Washington: Census Bureau; 2002.
- Illinois Department of Human Services, Division of Community Health and Prevention. Diabetes Control Program clinical practice recommendations. Springfield (IL): Illinois Department of Human Services, Division of Community Health; 1999.
- Stokols D. Translating social ecological theory into guidelines for community health promotion. Am J Health Promot 1996;10:282-98.