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Inner-City Residents in Rochester, N.Y., Receive Community-Based Care

Establishing a community-wide family health development program

SUMMARY

Project SHARED was a collaboration of four Rochester-based health and social service organizations (HCR Cares, Health Care Resources, The Health Association and Catholic Family Center) that developed a community-based project to enable chronically ill, low-income people in two inner-city neighborhoods to better manage their own health and to engage in behavior change that supported health.

Key Results

- Project team members enrolled 527 residents who had, or were at risk for, diabetes, high blood pressure, asthma (and other respiratory diseases such as chronic obstructive pulmonary disease) or heart disease. They helped residents design and undertake personal action plans to improve their health. By the end of the project, 199 residents still were participating.
- The four project partners worked with other community-based agencies to improve health and social program offerings in the two neighborhoods.
- Participants became engaged in improving their own health and initiated a stress management workshop, a walking club and social gatherings.
- Project staff wrote the *Project SHARED Manual: How to Guide to Launching a Community Health Model for the Under-Served Chronically Ill* that provides detailed information to help other communities develop and implement a similar program.

Three Profiles are illustrative of the changes participants made.

Key Findings

Project staff reported the following findings to RWJF. The first two findings are based on data analysis by the Center for Governmental Research, a Rochester-based nonprofit organization that conducts policy analysis.

- Two-thirds of participants moved forward by at least one stage of behavior change.

- Some 39 percent of participants became engaged in tracking their health status.
- Almost 90 percent of participants reported feeling better both physically and emotionally and said they could better manage their chronic diseases.

Funding

The Robert Wood Johnson Foundation (RWJF) supported this *unsolicited* project with three grants totaling $1,678,320 from February 2000 through January 2004.

THE PROBLEM

Social isolation and poverty impose a substantial burden of illness on many communities in the United States. In Rochester, N.Y., low-income, inner-city residents have poorer health outcomes and are less likely to use preventive services than other people, according to the *Health Action: Priorities for Monroe County: Adult Health Report Card* (October 1998). For example, at that time:

- 36 percent of African Americans in Rochester had diabetes, compared to 14 percent of whites.
- 39 percent of Rochester inner-city women had mammograms compared to 70 percent of suburban women.

HCR Cares, a nonprofit corporation founded in 1979, conducts research and disseminates information on community-based services.

In 1997, HCR Cares, Health Care Resources and The Health Association (all based in Rochester, and later joined in the project by Catholic Family Center) began to develop a model for a community-based project to enable chronically ill, low-income people in Rochester's inner city to better manage their own health. The model aimed to help people engage in behavior change that supports health. Staff from community-based organizations and trained community members would:

- Help each participant define his or her own health goals.
- Invite the participant to become involved in his or her own care.
- Focus on and strengthen the participant's existing abilities.
- Negotiate a plan of care between the participant and health care and social service providers.

Project developers called the model Project SHARED (Social Health Approach to Reinforcing Effective Disease Management).

Health Care Resources, Rochester's largest home health care provider, was founded in 1978. The Health Association, a nonprofit family support center founded in 1917, provides primarily substance abuse treatment, health education and advocacy and mental health services. HCR Cares and Health Care Resources are health agencies and The Health Association is a social service agency.

These three agencies worked together to conduct a pilot test of Project SHARED in two inner-city neighborhoods—northeast and southwest Rochester—in October and November 1998.

CONTEXT

In 2000, when the first grant was made, one of RWJF's focuses in the health area was on helping the nation better understand the epidemiology and health consequences of social isolation and pursuing community-oriented efforts to address the problem. In 2001, RJWF established a fourth goal area—health and well-being: to promote healthy communities and lifestyles—to address those factors outside medical care that have an important influence on health. Under this goal, RWJF supported projects that promoted healthy communities and lifestyles.

THE PROJECT

With funding from RWJF, four agencies partnered to implement Project SHARED on a larger scale in northeast and southwest Rochester: HCR Cares, Health Care Resources, The Health Association and Catholic Family Center.

The Rochester-based Catholic Family Center is a non-profit family support center founded in 1917 that provides a range of services including youth programs, adoption and foster care, substance abuse treatment, elder care, employment services, homeless shelters and refugee resettlement.

HCR Cares served as the lead organization for the project. RWJF gave the agency three grants totaling $1.7 million to support the project (ID#s 036887, 043023 and 043896) from February 2000 through January 2004.

A community leadership committee guided the project's implementation. In addition, a consumer committee made up of project participants provided feedback and made recommendations about the project. Each agency contributed approximately $10,000 of in-kind support (office space, support staff and computer resources).

Project staff screened 825 people and on a rolling basis enrolled 527 people from two neighborhoods who had, or were at risk for, diabetes, high blood pressure, asthma (and

other respiratory diseases such as chronic obstructive pulmonary disease) or gum disease (which research suggests is a proxy for heart disease).

Over the course of the project, 328 participants withdrew, leaving 199 participants at project end. Participants were primarily female, African American and Hispanic. The majority were single. They ranged from 18 to 75 years old. All had health insurance of some type.

Behavior-Change Action Plans

The project used a bottom up, rather than a medical approach to behavioral change. Participating individuals decided how to start their process of improvement, choosing where they wanted to begin, rather than having a health professional determine the most important place to start.

In this model, sometimes, the way to health improvement was a pathway through non-health challenges. The individual built a pattern of success necessary to take on some of the hard behavioral changes needed to improve health and health risk behaviors.

Participants developed and undertook healthy behavior action plans, with the support of project team members. The project team included a project director and a project manager at each of the four partner organizations as well as support staff, service coordinators (community members who provided outreach services and case management), community health nurses, a medical social worker, a health educator and an exercise instructor.

Community health nurses and service coordinators worked with each participant first to identify health or social issues that the participant wanted to address and their goal in managing each issue, and then to develop an action plan to reach that goal.

For example, if a person wanted to better manage her diabetes through an improved diet, her action would be to attend nutrition classes. Participants with multiple issues attended multiple programs.

If a participant's foremost issue was not health related—for example, a landlord problem—then project staff helped her resolve that issue first. Members of the project team referred participants to community physicians for medical services as needed.

Project staff helped participants identify and attend various programs to help them reach their goals. The programs were appropriate for the participant's language, culture, literacy level and other life circumstances. The project director reported that at the outset of the project such programs were few in number in the two neighborhoods so project staff had to create or adapt many programs.

For example, project staff translated a chronic disease management program being developed at Stanford University into Spanish and broke it down from long, two-to three-hour sessions to one-hour classes—a better fit for many participants' schedules. They held classes and workshops on exercise, nutrition, wellness, chronic disease management and stress management. Programs took place at the partner agencies or other locations in the two neighborhoods. For program descriptions, see Appendix 1.

The nurses and service coordinators helped participants with phone follow-ups, home visits and visits to community sites. The project director reported that these phone calls and visits were essential to building trust and helping participants negotiate the health care system and make their planned behavior changes. Project staff also helped participants understand and observe symptoms and track, as appropriate, certain of their own health status measures such as blood pressure and blood glucose levels.

Three participants' experiences are illustrative of the program:

- Cruz R., a 60-year-old Hispanic man with high blood pressure, diabetes, asthma and depression lost weight, reduced his blood pressure and blood sugar, and increased his lung capacity through five action plans. Read Cruz's profile.
- Rebecca C., a 61-year-old African-American woman with high blood pressure, depression and gum disease, helped control her weight and connect with other Project SHARED participants through exercise classes. Read Rebecca's profile.
- Ruby L., a 67-year-old African-American woman, learned how to control her blood pressure through exercise and diet. She reduced the number of medications she took from seven to two. Read Ruby's profile.

Tracking Behavior Change

Project staff tracked participants to assess behavioral changes and health status. Researchers at the Center for Governmental Research, under a subcontract from HCR Cares, assisted with study design and data collection and measured behavioral change among participants. Based in Rochester, the Center for Governmental Research is a nonprofit organization that conducts policy analysis.

To measure behavior changes in participants, the researchers used a research-based model that predicts change across many behaviors. The model describes five stages of a person's readiness to change behavior. The stages begin with "pre-contemplation"—that is, a person is not yet considering changing a behavior, say, adding more vegetables to her diet. The stages follow through to "maintenance"—a person has changed a behavior and is trying to maintain the change. See Appendix 2 for more information about the model.

The researchers measured stages of behavioral change both before and after project participants undertook an action plan. Project staff administered a patient satisfaction survey midway through the project and at project end.

RESULTS

Project staff reported the following results to RWJF:

- **Project SHARED enrolled 527 residents of two inner-city Rochester neighborhoods.** These participants had, or were at risk for, diabetes, high blood pressure, asthma (and other respiratory diseases such as chronic obstructive pulmonary disease) or heart disease. Project SHARED helped them design and undertake personal action plans to improve their health. By the end of the project, 199 residents were participating. The project director indicated that although the number of dropouts was high, dropout rates slowed as the project progressed.
- **The four project partners worked out ways to collaborate with each other and worked with other community-based agencies to improve health and social program offerings to residents of the two neighborhoods.**
- **Participants became engaged in improving their own health and initiated a stress management workshop, a walking club and social gatherings.** The walking club, designed to provide safe and enjoyable exercise while increasing social support, met for one hour twice a week. Participants also planned three holiday events and a summer gathering.
- **Project staff wrote the *Project SHARED Manual: How To Guide to Launching a Community Health Model for the Under-Served Chronically Ill* that provides detailed information to help other communities develop and implement a similar program.** The manual includes an overview of Project SHARED and sections on organizing the project, including the processes and challenges of developing a collaboration among four partners, screening, recruiting and retaining low-income neighborhood residents and case management and follow-up. Most sections conclude with lessons learned. Project staff disseminated about 30 copies of the manual, upon request, through the United Way and through RWJF. See the Bibliography.
- **Project staff made presentations,** including at the National Conference on Chronic Disease Prevention and Control and to community members.
- **Local newspapers, radio stations and television stations covered project activities.**

Findings

Project staff reported the following findings to RWJF. The first two findings are based on data analysis by the Center for Governmental Research.

- **Two-thirds of participants moved forward by at least one stage of behavior change.** This was calculated based on the number of action plans for which there were pre- and post-measures of behavior change. This exceeded the staff's goal of 50 percent of participants moving at least one stage forward. "The goal was ambitious. The fact that they exceeded that is wonderful," said Laura C. Leviton, PhD, RWJF senior evaluation officer.
- **Some 39 percent of participants became engaged in tracking their health status.** This also exceeded the goal, which was to engage 10 percent of participants in tracking their health status.
- **Almost 90 percent of participants reported feeling better both physically and emotionally and said they could better manage their chronic diseases.** This finding is based on the patient satisfaction surveys.

LESSONS LEARNED

1. **Recognize nonfinancial barriers to accessing health care that people who may be enrolled in Medicaid nonetheless often face.** Very low-income people who have technical access to health care through Medicaid may still not have access to the health services they need, especially in managing chronic diseases. Project participants cited language barriers, cultural beliefs, lack of transportation, lack of knowledge about disease and not knowing how to discuss medical information with their physicians as barriers to accessing health care. (Project Director/Woerner)
2. **Expect very low-income people to move around frequently.** Many project participants moved multiple times during this project, making it difficult for staff to keep track of them. (Project Director/Woerner)
3. **Develop satisfied customers, who can build a project's "business" and provide important feedback.** Active project participants were the best source of recruitment of additional participants and provided feedback about how the community perceived the project. (Project Director/Woerner)
4. **Choose partners carefully and build collaboration on trust.** This project was comprised of four organizations with unique cultures and operating styles. While the partners learned to trust each other and draw on each other's strengths, there were some problems based on differing views of the project. For example, while all partners placed high priority on providing services, individual agencies placed different values on collecting data. (Project Director/Woerner)

5. **Define clear lines of authority in collaborations.** At times, there were no clear lines of authority among the four partners, and it took time to make decisions within each agency and then among all agencies. (Project Director/Woerner)

6. **Consider timing when launching projects; summer is not an optimal time for indoor projects.** Project staff launched the project in the summer, and had difficulty getting participants interested in indoor activities and classes. (Project Director/Woerner)

7. **Hire community members to build the trust of project participants, but be aware that they may lack certain technical skills.** Community members who worked as service coordinators in Project SHARED had the trust of project participants, which was crucial since participants had little trust in the health care system. However, they lacked computer skills and often did not complete documentation, making data analysis difficult. (Project Director/Woerner)

8. **Realize that programs aiming to change people's individual behavior may be costly in terms of staff time and other resources.** "We showed how costly it was to change behavior. For many people we had to walk along with them until they could gain the capacity to walk through the health care system." (Project Director/Woerner)

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APPENDIX 1

Project SHARED Health Programs

- **Motion Promotion** provides a safe and effective exercise program three days a week to people with chronic diseases or other functional disabilities. The exercises consist of range of motion activities, muscle conditioning, balance, coordination and flexibility. Movements have been incorporated into exercises that can be performed while seated in a chair or standing in a warm water pool. Participants are encouraged to exercise at their own pace.
- **Nutrition Class** leads people toward dietary behaviors that result in improved health through a minimum of six weekly classes, usually one-hour each. Class size is 20–25 participants. Content includes group discussions aimed at identifying participants' priorities and the hands-on preparation of nutritious meals that reflect the participants' culture, financial resources and access to ingredients in their neighborhoods.
- **Wellness Class** is a four-session program targeting people living with chronic disease to increase their knowledge of their disease and improve their disease management skills. Class size ranges from four to 25. Content includes disease-specific education, the development of problem-solving and action-planning skills and group support for disease management activities.
- **Chronic Disease Management** is a six-week program targeting people with a variety of chronic illnesses to improve their disease management/self-care capacities through behavior change and social support techniques. Class sizes are from 6 to 15 people, and each session is one hour. Content supports disease-related behavior changes through education, targeted behavioral interventions and social support.
- **Diabetes Mellitus Workshop for Spanish Speaking Chronically Ill** helps people who speak Spanish and have diabetes to monitor and manage their disease. Three sessions.
- **Stress Management Workshop** is a one-hour workshop to help people improve their health through stress reduction. Class size is 10–35 people. Content includes symptoms of stress, the effects of stress on the body and stress management techniques.

APPENDIX 2

The Five Stages of Change

These stages are delineated by the Prochaska Transtheoretical Model of Change:

1. **Pre-contemplation:** Not intending to take action in the next six months.
2. **Contemplation:** Intending to change in the next six months.
3. **Preparation:** Intend to take action in the next month.
4. **Action:** Have made changes in the last six months.
5. **Maintenance:** Working to prevent relapse.

APPENDIX 3

Profiles

PROFILE: Cruz R. Returns to a Normal Life

Living with high blood pressure, diabetes, asthma and depression had turned Cruz R. into a recluse prone to aggressive outbursts. Each year, the 60-year-old Hispanic man was hospitalized as many as six times for uncontrolled high blood pressure and blood sugar. He was short of breath after walking 20 steps and sometimes needed oxygen to get through the night. After joining Project SHARED in June 2000, Cruz became outgoing and began to lead a normal life.

Cruz wanted to improve his health but didn't know how to do it. The Project SHARED nurse and service coordinator helped him figure out which lifestyle changes he needed to make and the actions he could take to make the changes. Then they helped him develop and implement five action plans.

Cruz started by attending nutrition classes to learn how to manage his diabetes by eating right. Then he worked on learning how to record his blood sugar readings, determine the cause of his asthma attacks, quit smoking, eliminate alcoholic and sugared drinks from his diet, exercise and reduce the number of medications he took. He learned how to use the glucometer project staff gave him, attended exercise classes and later purchased gym equipment and joined a walking program.

Since Cruz's health problems were so complex, project staff arranged for a nurse to visit him at home one to three times a week for nine months. The nurse coached and supported him in his action plans, taught him how to manage his health, monitored his vital signs and helped him track his 19 medications. The nurse quickly learned that Cruz, who is functionally illiterate, was not taking his medications correctly, primarily because he

couldn't read the directions on the containers. She taught him the purpose of each medication, and developed a schedule for taking them he could easily follow.

By October 2001, 15 months after he enrolled in the program, Cruz had not been hospitalized or needed oxygen for 10 months. He had gone from taking 19 medications a day to 6. Cruz lost 36 pounds, reducing his body mass index from 38 to 33. His blood pressure was down and his blood sugar was down. His lung capacity had increased.

Fifteen months after enrolling in the program, Cruz:

- Had not been hospitalized or needed oxygen for 10 months.
- Had gone from taking 19 medications a day to 6.
- Had lost 36 pounds, reducing his body mass index from 38 to 33.
- Had lowered his blood pressure and blood sugar and increased his lung capacity.

This profile is based on a case history provided by the project director, Louise Werner.

PROFILE: Rebecca C. Develops Interest in and Hope for Her Health

Rebecca C. was afraid of dying early as her parents had and felt isolated. After enrolling in Project SHARED in September 2000, the 61-year-old African-American woman stopped living in fear, developed a preventive health attitude and became connected to her community.

Rebecca watched both of her parents die young from strokes. Since having a stroke herself due to an aneurysm in 1995, she lived in fear of following in their footsteps. Rebecca was able to conquer this fear with the help of the Project SHARED nurse and service coordinator, who consulted her physician and learned that Rebecca was not likely to have another aneurysm.

With hope for her future, Rebecca was ready to tackle her real health problems: high blood pressure, depression and gum disease (a marker for heart disease). She was taking eight medications for these problems.

Rebecca worked with the Project SHARED nurse and service coordinator to develop and implement five action plans. In her first action plan, she focused on weight control by attending the Motion Promotion exercise class, and resolved her gum disease by visiting the dentist. Through Motion Promotion, she began to feel connected to other Project SHARED participants.

In her other action plans, Rebecca set goals to learn healthy food preparation, lose 10 pounds, reduce her caloric intake, and increase her activity level. She attended nutrition

classes then used the cooking techniques she learned at home, reduced unhealthy snacks and high-fat foods and exercised regularly.

By October 2001, 13 months after she enrolled in the program, Rebecca had reduced her daily medications from eight to one. She felt in control of her blood pressure, which was down. Rebecca had lost 24 pounds. Her depression and gum disease were under control.

Thirteen months after enrolling in the program:

- She now took one medication daily, down from eight.
- She felt in control of her blood pressure, which was down.
- She had lost 24 pounds, and was controlling her depression and gum disease.

Rebecca was passionate about preventive health and Project SHARED. Within her building and among her new Project SHARED friends, she advocated for exercise and weight loss.

This profile is based on a case history provided by the project director, Louise Werner.

PROFILE: Ruby L. Uses Exercise and a Healthy Diet to Control Arthritis and High Blood Pressure

Ruby L. was a compulsive eater—especially of potato chips—who found it difficult to move around her apartment because of arthritis. The 67-year-old African-American woman also had high blood pressure and bleeding gums. After joining Project SHARED in September 2000, Ruby was exercising and eating right—and feeling much better.

When Ruby first came to Project SHARED, her gums bled sporadically. The Project SHARED nurse sent her to the dentist, where Ruby learned that the bleeding gums were due to poorly fitting dentures. A new set of dentures solved this problem.

The Project SHARED nurse and service coordinator then helped Ruby develop and implement three action plans. The first focused on starting to walk 30 minutes a day three times a week. Within weeks, Ruby found that the walks really helped her in the morning, when her arthritis was most severe. She began exercising every day.

Ruby then worked on developing better eating habits and learning more about her high blood pressure and arthritis. She attended nutrition classes, where she learned that she was always hungry because she didn't eat proper meals. The nutritionist helped her develop a diet that met her needs. Ruby stopped eating potato chips and eliminated salt from her diet.

To understand how she could control her high blood pressure and arthritis, Ruby attended disease management classes. She even asked her physician for more information, which

she brought in to share with her classmates. Ruby also learned to check her blood pressure with a home machine.

By October 2001, 13 months after she joined the program, Ruby had lost 14 pounds. Her blood pressure was down. She had reduced the number of medications she took from seven to two.

Thirteen months after joining the program, Ruby had:

- Lost 14 pounds
- Lowered her blood pressure.
- Eliminated five of her seven medications.

This profile is based on a case history provided by the project director, Louise Werner.

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