

ESSAY

Social Determinants of Health: The Community as an Empowered Partner

S. Leonard Syme

Suggested citation for this article: Syme SL. Social determinants of health: the community as an empowered partner. *Preventing Chronic Disease* [serial online] 2004 Jan [date cited]. Available from: URL: http://www.cdc.gov/pcd/issues/2004/jan/03_0001.htm

While we in public health know the importance of involving community partners in our programs, we also know how difficult it is to do. The challenge of involving the community is especially difficult if one has been trained, as I have been trained, to be an arrogant, elitist prima donna. I am the "expert," after all, and I help people by sharing my expertise.

Let me begin by describing my own humbling attempts at community involvement through a smoking-cessation project I directed several years ago in Richmond, California. I came to the project with a dismal record in assisting people individually to quit smoking, so in the Richmond project I resolved to take a different tack; I designed the Richmond project as a community project. By having a block captain in every neighborhood in Richmond, I planned to involve the business community, the schools, and community groups. My idea was to change the climate in Richmond with regard to smoking by challenging its acceptance, its values, and its attractiveness.

Toward that end, I wrote a brilliant 5-year research grant and sent it to the National Cancer Institute (NCI). It was a bold, expensive project at \$2 million, and for that reason NCI sent a large site-visit team to discuss it. By the end of the visit, NCI agreed that my project was brilliant, and in fact later used the design as the basis for the nationwide COMMIT study conducted in more than 20 communities around the nation.

With NCI's enthusiastic support, we proceeded to imple-

ment the project for 5 years. Our team worked hard, followed the design carefully, and at the end of 5 years we compared the results we achieved in smoking cessation with our 2 comparison communities, Oakland and San Francisco. We found no difference in smoking quit rates. It was only later, after I finished brooding, that I understood the challenges of that community-partnership model. Richmond is a very poor city. It has many unemployed people, high crime and drug use, very few health services, and air pollution from nearby oil refineries. Of all the problems faced by people in that community, I doubt that smoking was very high on their priority list. But of course I had never asked them about their priorities, and even if I had, I probably would have persisted with my plan anyway; I was, after all, the expert.

I learned another painful lesson from that experience. Early in the Richmond project, a group of teenagers came to us and said they would like to make a rock video about smoking. They offered to write the music and the words, but wanted our help to invite a famous rock star — I can't remember her name now — to spend one day on the project, and they wanted a music-video director from Hollywood to come, too. We hadn't budgeted for such expenses, but we did it anyway. The rock star came in her limousine and the Hollywood director showed them how to set up the scenes for filming. Afterward, the students showed the video they produced at a large movie theater in the community. They printed the tickets for this show, made the advertisements, and served as ushers, and the sold-out show received a long standing ovation from the audience. The video was subsequently shown in many places around the world, and the community received royalty money for it.

Unfortunately, the video was not part of my brilliant research plan, and we had no money to evaluate its bene-

fits. So the one thing in the project that came from the community — and incidentally the one thing that probably made the biggest impact — was not conceived, implemented, or evaluated by our research team. So much for my brilliance.

To add to my embarrassment, the nationwide COMMIT study, based on my Richmond design, reported its results: the study failed to show a difference in smoking cessation rates between the study and comparison communities.

Why was it so hard for us — for me — to see the importance of embracing the community as an empowered partner? Part of the answer is that public health experts focus on diseases and risk factors. Although we have important messages to convey to people, we also recognize that people have lives to lead, and often there is a gap between our focus on diseases and our intent to convey information with enough impact on people's lives to foster change.

In my view, there are 3 major problems we should confront in thinking about community partnerships and community empowerment. The first problem is that we have such a difficult time identifying disease risk factors. Identifying these factors is important, because we hope that if people knew about their risk, they would rush home and change their behavior in the interest of good health. Consider the problem we've had identifying risk factors for coronary heart disease, which is the number-one cause of death in this country. We now know the big risk factors for the disease — cigarette smoking, hypertension, and high serum cholesterol — and there are perhaps a dozen more risk factors such as physical inactivity, obesity, diabetes, and so on. Taking all of the known risk factors together, we can explain about 45 percent of the coronary disease that occurs, but the rest is unexplained.

The second problem is that even when people know about their risk, they find it difficult to change their behavior. There are many examples that describe the failure of wonderfully designed and executed interventions to help people lower their risk. In fact, I participated in one of them: the Multiple Risk Factor Intervention Trial. This \$200 million study involved men in the top 10 percent risk category for developing heart disease. We screened 500,000 men in 22 cities and selected 12,000 highly informed and motivated participants for a 6-year trial. We asked them to change their diet, take high-blood-pressure medication, stop smoking, and report frequently to the

clinic. Together, we cooked low-fat meals and read labels at supermarkets. We conducted a superb intervention program, but the trial failed. After 6 years, there was no statistically significant difference in heart disease rates between our group and the control group. Few men in our group changed their behavior.

The third problem, however, is the most challenging of all. Even if those at risk did change their behavior to lower their risk, new people would continue to enter the at-risk population at an unaffected rate. This influx occurs because we rarely identify and intervene on those forces in the community that cause the problem in the first place. This last problem is a major challenge for public health. If our goal is to prevent disease and promote health, I don't think we can accomplish it by focusing exclusively on individual diseases and risk factors. And we can learn a valuable lesson from the success we have had in preventing many infectious diseases. Although vaccines account for some of that success, most success is because of an improvement in the environment, specifically the way we classify diseases. Disease classifications are in terms of water-borne diseases, food-borne diseases, air-borne diseases, and vector-borne diseases, meaning that while the classifications are not of much value clinically — for example, in the treatment of individual cases — they are of great importance in telling us where diseases are coming from and where we should direct our prevention efforts.

Do we have a similar classification system for the non-infectious diseases of concern today? That's an interesting question. Suppose we wanted to develop a community-based framework for the prevention of disease and the promotion of health. What would it look like? The first job in developing such a framework would be to identify the most important population determinants of disease. Where should we focus our attention? We know the answer to this question, but until very recently we haven't wanted to talk about it or do anything about it. The most important social determinant of disease is social class. Social class has been an overwhelmingly important risk factor for disease since the beginning of recorded time, and it's related to virtually every cause of disease. We have all made this observation, but we're not sure what to do about it. If revolution is the only useful intervention to remedy the ills of social class, it is not surprising that public health professionals have instead pursued more straightforward research such as the relationship between physical activity and diabetes.

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, Centers for Disease Control and Prevention, or the authors' affiliated institutions. Use of trade names is for identification only and does not imply endorsement by any of the groups named above.

If you were willing, however, to take on the issue of social class as an intervention focus, how would you intervene? Money? Education? Nutrition? Medical care? Housing? Jobs? Environment? Which of these is most important? The answer, of course, is that these factors are all important and they are inextricably bound, and the frustrating complexity of social class as a risk factor leads most of us to change the subject and study something else.

There has been a breakthrough, however, in this line of research. A few years ago Dr. Michael Marmot studied coronary heart disease in 10,000 British civil servants and made an interesting discovery. He found, as you would expect, that workers at the bottom of the civil-service hierarchy — guards and delivery people — had heart disease rates 4 times higher than workers at the very top of the hierarchy. But Marmot also observed a gradient of disease from top-to-bottom of the civil-service hierarchy. Workers at the top had the lowest rates of disease, but those one step below them — professionals and executives, doctors and lawyers — had heart disease rates twice as high as those at the very top.

We might be able to explain the high rates among those at the bottom in terms of poverty, poor education, inadequate nutrition, or poor housing, but that would not explain why doctors and lawyers had rates of disease twice as high as those at the very top. Doctors and lawyers are not poor; they do not have bad educations or poor medical care or poor housing, and yet they have disease rates twice as high as those above them. A very similar gradient has now been seen for virtually every disease in every industrialized country in the world.

This is a major breakthrough in our thinking, and Marmot's findings give us something to investigate. How can we explain the gradient? Many researchers are working on this question, but my own hypothesis involves what I call "control of destiny." By this phrase I mean the ability of people to deal with the forces that affect their lives, even if they decide not to deal with them. I think this is what empowerment means. Even if control of destiny and empowerment are not worthwhile concepts — and I think they are — we need other ideas like them. The point is that to prevent disease, we must intervene on those community forces that cause disease problems, and social class is the obvious and most important factor. But because social class is also a complex issue, we should identify concepts related to the social-class gradient that are amenable to

intervention. If "control of destiny" and "empowerment" are important factors in the cause of disease at the community level, they are also factors for which we can develop interventions.

Additionally, if we can move away from a focus on diseases and risk factors and begin to think about community and social forces, we can also relate to the community in a more meaningful way and stand a better chance of involving the community as an empowered partner. One example of such a partnership is through a grant my group received recently from the Centers for Disease Control to study fifth-grade children in a low-income community near Berkeley. The grant focuses on cigarette smoking and other drug use, violence, poor school performance, sexual behavior, and so on, but we decided not to study any of those things. We decided instead to focus on the fundamental issue underlying all of these problems; we decided to focus on hope. If these children, mostly from minority groups and very poor families, had no hope for the future, what difference would it make if they smoked or used drugs or missed school or engaged in violent behavior? So we decided to help these children see that they could have a future. We're working with them over a 3-year period to teach them ways of implementing their dreams: how to make things work for their benefit; how to select a problem and succeed in solving it; how to develop strategies for getting done what they want to get done; how to take control of their destiny. We trained high school students from the fifth-graders' own community, along with hand-picked Berkeley graduate students, to work with the children as partners. The project is just starting, and we have our fingers crossed.

Our study of 2,000 San Francisco bus drivers offers another example of empowerment. The project started when one of my former students, as director of health for San Francisco city employees, began supervising physical exams for bus drivers. Among drivers over the age of 60, the prevalence of hypertension was 90 percent, so we launched a study. But then we noticed that drivers complained of back pain, then gastrointestinal and respiratory difficulties. We also observed high rates of alcohol use after work. We secured more funding and designed more interventions, but our work did not solve the essential problem. We were so focused on specific diseases that we failed to recognize the fundamental problem: the job.

We then investigated why the job caused so many prob-

lems. Computers devised a rigid bus schedule that allocated time depending on the number of buses available, but the computers were allocating time in a city with a bus shortage. Drivers had to get from Mission and Army Street to Mission and Geneva Street, for example, in 2 minutes. A fast ride in your Ferrari on Sunday morning would take longer. In addition, because drivers were penalized when they arrived late, they gave up rest stops and dashed into fast-food restaurants instead. And since the drivers were almost always late, the passengers were almost always angry. Drivers lacked control over a host of variables such as traffic and terrible shift arrangements, and drove during both morning and evening rush hours without enough time to go home in between shifts. At the end of a long day, many visited the local tavern. When they got home, they did not often socialize, but went to bed, only to get up at 4:00 a.m. to begin another grueling day.

Yes, they have health problems and should be helped, but obviously it's the job that needs to be fixed, and we are trying to do that by focusing on control of destiny and empowerment. But to develop a partnership with the community, we will have to resolve 3 problems:

1. The challenge of inappropriate funding mechanisms.

It is important that we recognize the pervasiveness of funding mechanisms that reinforce a clinical, individual approach to disease. Most research grants are funded to deal with specific diseases. Most training grants do the same, and most of the researchers in the field today are working in programs that focus on a particular disease or a particular risk factor. This emphasis on diseases produces a group of disease experts and expertise-driven intervention programs. This approach is effective as long as there are other programs that focus on fundamental issues affecting people's daily lives. By also addressing these "people issues," we have an opportunity to work with people in the community to become empowered partners.

2. The challenge of working with people in different disciplines.

Inevitably, a focus on the community requires that we in public health think across disciplinary lines, and in the past we have not done this very well. I was the graduation speaker at my school of public health 2 years ago, and I noted that the students in the graduating class represented a wide variety of disciplines: virology, endocrinology,

medicine, mathematics, engineering, political science, geography, genetics, sociology, nutrition, anthropology, economics. While we all had different interests, we were united in our desire to help make the world a better place; I suggested that as they went forth to do that, they would likely fail because we at the university had failed them. We had trained them in specific disciplines, but they would soon discover that the problems people face transcend those disciplines and involve schools, parks, roadways, housing, employment, schools, crime, and politics. As faculty we were trained in disciplinary silos, and we continue to receive research and training grants that reinforce our silos; moreover, we will continue to train people as we have been trained. If this cycle continues, it is unlikely to lead to collaboration with empowered community partners.

3. The challenge of intervening at many levels.

So far, I have emphasized that we have not done a very good job in helping people change their behavior, but, as we all know, people change their behavior all the time, on their own and without our help. A good example is cigarette smoking: the prevalence of smoking in California has decreased from 43 percent to less than 20 percent in recent years. This achievement is phenomenal, and it far outstrips the successes we in public health have had in our smoking-cessation programs. The decline in smoking was because of a series of interventions at every level: we learned about smoking addiction from research in experimental psychology and applied that knowledge; we learned about techniques of behavior change and benefited from that knowledge; and we informed people about the health risks of smoking. But we also raised the price of cigarettes, limited access to cigarette machines, enforced strict limitations on advertising in magazines and on billboards, and outlawed smoking in many public places. We developed a health intervention that involved a variety of partnerships and went far beyond the narrow confines of the health field. And it worked. Most of the successes we have achieved in behavior change have come about because they have been the subject of a multi-pronged, multilevel, multidisciplinary approach. These approaches involve not only information but also regulations and laws, mass media campaigns, workplace rules, and better environmental engineering and design.

And we have had other successes. Despite the challenges I mentioned in coronary heart disease, since 1970 there

has been a tremendous decline in death rates from this disease, one of the most dramatic declines in disease ever recorded. Coronary heart disease is still the number-one cause of death, but such a dramatic decline in mortality is an impressive achievement; it's because of not only the tremendous advances in the medical treatment of people who already have the disease but also because people have in fact changed their high-risk behavior. And the death rate from many other diseases is also declining. Obviously, we are doing something right, but, as is true of most topics, even success is complicated. Death rates have gone down, but the gap in health between those at the top and those at the bottom of the social-class gradient has widened and continues to widen every year.

These are difficult issues, and I have struggled with them for many years. Especially difficult is the problem of working with members of the community as empowered partners. And by "community" I mean any group of people we target for intervention, whether they are fifth graders or MRFIT participants or residents of Richmond, California, or bus drivers. Whatever the group, I have not done well in the past working with them. After considering my efforts, I have begun to think about where we should direct our efforts in public health. The medical-care system is under enormous strain in this country, and baby boomers haven't even entered the older population yet. When they do, in 2020 or 2030, the number of older people in this country will double. If we think our medical-care system is in trouble now, we ain't seen nothin' yet. Our only hope is to develop better proactive strategies for preventing disease and promoting health, rather than waiting to fix problems after they occur. And to carry out those strategies successfully, we will have to work with the community as an empowered partner, which ultimately means changing our public-health model at a fundamental level. We will have to change the way we classify disease, train a new generation of experts, change the way we organize and finance public health education and research, and deal with our arrogance. These are very difficult and humbling challenges, but I know we can meet them. We really have no choice.

**S. Leonard Syme, Professor Emeritus of
Epidemiology
University of California, Berkeley**

Adapted from his presentation at the 17th National
Conference on Chronic Disease Prevention and Control
St. Louis, Missouri, February 19-21, 2003