INTRODUCTION

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In 1985, *The Health Detective's Handbook*, the early version of this book, was launched with much enthusiasm and optimism. We were convinced that lay persons could bring to bear the power of science in addressing their concerns: were they sicker than other communities? Could this be related to their physical environment? It was our further hope that those who could verify that a problem truly existed could use this information to spur further study by health agencies. Once a problem was recognized, governmental or legal action could be taken to mitigate the harms and risks.

Today we are even more convinced of the power of individuals, working together. Every year the list of victories grows longer. Individuals see a health threat or potential threat, join in with a group of neighbors, then fight this threat to their families, homes, and communities. Evidence that there is a problem can be helpful in the organizing effort, but the victories are based on moral arguments, not scientific ones.

EVIDENCE OF HEALTH EFFECTS

Community groups are always asked to prove harm. But the scientific tool available for use, namely traditional epidemiology, is crude and insensitive in most of these cases. In 1989, the Agency for Toxic Substances and Disease Registry sponsored a conference on epidemiology in a community setting. Papers presented were compiled as Supplement No. 1 (July 1990) of the *American Journal of Epidemiology*.

The keynote speaker, Dr. Kenneth Rothman, noted the near impossibility of finding the causes of clusters of disease from environmental exposure. Affected neighborhoods or groups often are too small to allow for "useful" epidemiological study. Reported effects and exposures are varied and tend to be low. The publicity generated by a percep-

tion of a possible effect makes unbiased gathering of information very difficult.

Another speaker, Dr. Raymond R. Neutra, claimed to be less pessimistic. Some characteristics of certain disease clusters can make them amenable to solution. These can be loosely grouped into two categories: 1) the exposure must be such that it can be identified with a particular agent and 2) the substance and illness it may be causing must have characteristics that help make the results of the study statistically significant. These too may be impossible conditions to satisfy. Exposure is most often to a variety of substances and these chemicals rarely cause unique conditions. Instead, expected effects usually are increases in background rates of common illnesses.

While epidemiology itself is a relatively insensitive tool in these cases, those wielding this tool often will have an institutional bias against finding effects. A positive study, it is feared, will lead to unpleasant political effects ranging from anger against the administration that allowed the harmful activity to demands for something to be done now. In most cases, if an agency did find positive results it would be unable to alleviate the situation. Economic effects such as depressed housing markets and lost development also may occur.

There are several techniques public health agencies can use to *not* find problems. As noted above, epidemiological studies are relatively insensitive, especially considering the small groups of exposed persons and uncertain exposures characteristic of community problems. One can further minimize the chances of finding positive results in the choice of the control group and exposed group. When differences are found, lifestyle factors, such as smoking habits are often mentioned as probable causes. (See Ozonoff and Boden, 1987.)

The U.S. Centers for Disease Control has conducted over one hundred cancer cluster investigations over two decades. None revealed any clear cause (Caldwell, 1990). There are 35 chemicals or processes that the International Agency for Research on Cancer has judged to be known human carcinogens. Only one was found through reports of cancer in a community. We also know that industry is making little effort to identify possible carcinogens. A survey of the U.S. manufacturers of 75 animal carcinogens in general commerce found only eight were the subject of completed epidemiological studies and five of ongoing studies (Karstadt and Bobal, 1982).

The Health Detective's Handbook recommended that health survey results be used to request further study by state and local agencies. For the reasons noted above, we now believe that further formal study may be counterproductive to a goal of remedial action. We now believe that more attention should be paid to organizing your community.

USING THE TOOLS AT HAND

We think it essential for the community to gather as much information as possible and practical about the problems they may face. Hence this book. If you want something done because you feel your neighborhood suffers ill health, the information you develop through techniques discussed in this book will help you make a plausible argument. This manual also can focus your efforts. For example, you may find indications that the possible source of exposure is your drinking water rather than the industrial facility nearby. The epidemiology that we are advocating may provide hints that traditional epidemiology cannot because agencies and academic institutions often do not have the interest, money, or human resources to investigate every potential problem. Epidemiology is a labor-intensive field. The motivated members of a community, who believe they may have a problem, are in the best position to ensure that the needed hours of labor are given to the project.

You are not seeking the holy grail. On the one hand, no study can provide unequivocal evidence that will immediately prompt industry, agencies, or politicians to act. On the other hand, you are not exploring an always illusive goal. A review of data on hazardous waste sites found indications of health effects in spite of the limitations of epidemiology and the few sites studied (National Research Council, 1991). Epidemiological studies reviewed provide evidence of increased rates of spontaneous abortions, birth defects, neurological impairment, and cancer in some populations living near hazardous waste sites.

There is a tradition that those who wish for change in the accustomed way of doing things bear the burden of proof for the need for change. That has meant that communities questioning industrial emissions or the siting of facilities have been asked to show that they have been or will be hurt. But unquestionable proof will never exist. That kind of evidence is almost never possible in the setting of a traditional epidemiological study. Even if it were possible, it would take years; so that while information accumulates, so does the number of victims. Many successful groups challenge the burden of proof. They point out that our society has accepted practices based on inadequate evidence. While industry has the right to operate and to seek profits, the community has the right to clean air, water, and soil. This argument will be one of your most powerful tools.

USING THIS HANDBOOK

Epidemiology is the study of the various factors determining how often, in how many people, and in which people disease occurs. This manual

will guide you step by step through a descriptive study of the overall health of members of your community, geared toward environmental issues. We believe there are usually enough resources within the community itself, in terms of time, energy, common sense, and intelligence, that a high-quality general health survey can be done at the local level. You should be able to conclude either that there are no adverse health effects owing to toxic substances or that there really is an increase in diseases or conditions that could be related to toxic substances.

We have tried to write so we can be understood by an intelligent person with a high-school education or by a person who has had some college education but not in the biological sciences. We recommend using a medical dictionary, particularly for terms relating to health effects or diseases, but most actual diseases are given by name only and not by detailed description to avoid self-diagnosis by the general reader.

The need for a manual on environmental investigation for non-professionals has become apparent as communities have sought help to investigate perceived health problems. In some instances citizens in neighborhoods close to industrial sites, such as petrochemical plants or waste disposal areas, have become concerned about the risk these sites represent to the health of their families. In other instances members of a community have become aware that several of their neighbors were affected by the same illness. In almost all cases, the concerned citizens have been frustrated in their attempts to interest local or state agencies in assisting them. Limited budgets and lack of resources restrict the ability of government agencies to respond to such concerns.

Is there an alternative to traditional epidemiologic studies? Can a meaningful data base be generated without the costly traditional approach to community studies? We believe that such an alternative approach exists. Motivated citizens, given the proper guidance, can generate meaningful data. They can, with professional support, determine the probability that a problem is present. The goal of this manual is to provide guidelines to permit citizens to pursue such a study of their own.

CHEMICAL ALERT! A COMMUNITY ACTION HANDBOOK