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Ethics-A Bridge for Communities and Scientists: A Curriculum for Community Outreach and Education

Ann Freeman Cook

University of Montana - Missoula, ann.cook@umontana.edu

Helena Hoas

University of Montana - Missoula, helena.hoas@umontana.edu

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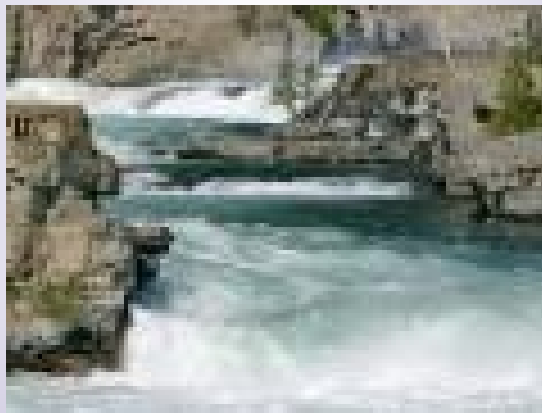
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Ethics: A Bridge for Communities and Scientists



**A Curriculum for Community
Outreach and Education**

**By
Ann Freeman Cook, Ph.D.
Helena Hoas, Ph.D.**

Ethics: A Bridge for Communities and Scientists
A Curriculum for Community Outreach and Education

Ann Freeman Cook, Ph.D.
Director, National Rural Bioethics Project
Research Professor,
Department of Psychology - Corbin 341
The University of Montana
Missoula, MT 59812-7397
[Http://www.umt.edu/bioethics](http://www.umt.edu/bioethics)

Helena Hoas, Ph.D.
Research Director
National Rural Bioethics Project
Research Professor,
Department of Psychology
343 Corbin Hall
The University of Montana
Missoula, MT 59812-7397
<http://www.umt.edu/bioethics>

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The Team

The Ethics-A Bridge for Communities and Scientists (E-ABCs) team includes:

Ann Freeman Cook, Ph.D., Research Professor
Department of Psychology, University of Montana

Helena Hoas, Ph.D., Research Professor
Department of Psychology, University of Montana

Elizabeth A. Putnam, PhD
Associate Professor
Center for Environmental Health Sciences, Biomedical, & Pharmaceutical
Sciences, University of Montana

Helen Clarke, AA, Site Manager in Libby, Montana

Katarina Guttmanova, Ph.D., Statistician

Dixie McLaughlin, BA., provided assistance in the initial stages of the project.

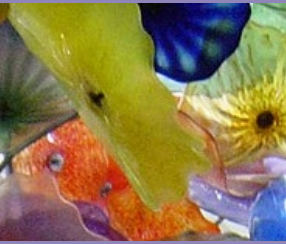
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Table of Contents

Chapter 1: Setting the Stage: An Introduction to Libby


Page 1



Chapter one provides background information on the community of Libby so that readers will understand the context in which the E-ABCs project was developed. In many ways, the story of Libby shows why it is so important to find many ways to think about issues such as environmental disasters.

Chapter 2: Falling Apart: A Community Faces a Growing Problem


Page 16



Characteristics of Libby are discussed and compared and contrasted with other Superfund sites. This section also offers tools and approaches that help define the community culture and develop community leadership.

Chapter 3: Picking Up the Pieces

Page 28



This section focuses on processes that support community-wide decision-making. It discusses various data gathering techniques and offers suggestions and tools that support community engagement.

Chapter 4: Conducting Research in an Ethical Fashion


Page 46



This section addresses ethical issues that must be considered when conducting research in environmentally compromised communities.

Chapter 5: Engaging Healthcare Providers in Ethical Discourse


Page 62



This section discusses the ethical responsibilities shouldered by healthcare providers who work in environmentally contaminated communities. A basic ethics primer, tools for ethical decision making, and case studies are provided.

Chapter 6: Engaging the Educational Community

Page 86



The materials in this section are designed to encourage educators to recognize and discuss with their students the range of issues associated with environmental contamination. Suggestions for classroom discussion, teaching modules, and other resources are included in this section.

Chapter 7: Stepping Up to The Plate


Page 114



This section discusses the roles of various players - federal, state and local - when facing environmentally challenging issues.

Chapter 8: Moving On

Page 134



The challenges that accompany an environmental disaster are not easily resolved but as this section illustrates that practical approaches, such as the Precautionary Principle approach, and meaningful activities can contribute to community's wellbeing.

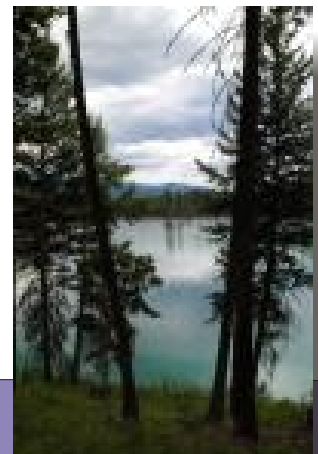
Guide to Using the Manual

This manual for community education and intervention was produced by the Ethics: A Bridge for Communities and Scientists (E-ABCs) project. Funding for this effort was provided by the National Institute for Environmental Health Sciences (NIEHS) through its Ethical, Legal and Social Implications (ELSI) competition, grant number R25-ESO-12073-05. ELSI projects are designed to translate scientific information in ways that allow the public to make informed decisions about health and wellbeing.



The E-ABCs project was conducted in the community of Libby, Montana where it examined the ethical implications of asbestos contamination. The E-ABCs team included the following professionals: ethicist, geneticist, social scientist, and outreach coordinators. Through this effort, we wanted to explore how an awareness of ethics can support and enrich community dialogue.

A community level effort of this sort is rather unique. Many community members lack familiarity with ethics as a discipline and so ethics can seem like an academic subject, one that has strange and unfamiliar terms and concepts. Some community members may fear that an ethics project will focus on particular moral values and so increase tensions and disagreements among residents. Others may feel that an ethics project will produce lots of conversations, but few practical actions.





Ethics, however, is a useful and practical subject that can help us find the best course of action in the face of conflicting choices. Its tools and strategies can help us examine the moral basis of human behavior. That examination can help us recognize who does what to whom and how and what we can do about it. Ethics is part of who we are and everything we do. That assertion can be evidenced in the quotes that are highlighted on many of the pages in this manual. The quotes are from community members; they show the range of perspectives, visions, beliefs, and expectations that emerge in a community that faces environmental contamination.

We began this project with some guiding principles in mind. We wanted to create a dialogue that could involve as many members of the community as possible. So instead of talking about what ethics involves, we tried to create activities that showed what ethical approaches look like. We wanted to help residents differentiate opinions from evidence and so tried to find ways to translate scientific information in clear and understandable terms. Such translation is important because it is hard to adopt healthy behaviors if we do not understand the risks that we encounter. We wanted to help people understand alternative points of view and so tried to develop activities that involved many different groups and many different perspectives. When we understand alternatives, we can make better decisions about important issues like the diagnosis and treatment of illnesses.



Ethics does have a formal language, but it has a common and accessible language as well. An ethics project can help us find values that can be practiced and appreciated in a pluralistic, democratic society. An ethics project helps us understand that though issues do not always have single right or wrong answers, we can always make efforts to respect and include one another, to avoid causing harm, to be fair, and to be kind.

This manual is not intended to be read cover to cover. Rather, readers can use the different modules according to the needs of local audiences. Hopefully, the stories we tell will make it easier to imagine and then design ethical, healing approaches for your own communities.

Chapter 1

Setting the Stage: An Introduction to Libby

“It was
a job.
You
needed
work.
You
took
the
work.”

A Promising Mineral

In 1919, businessman Edward Alley discovered a mountain of vermiculite ore that was adjacent to the community of Libby, Montana. In fact, Alley discovered what was believed to be the world's largest deposit of vermiculite. Alley was an entrepreneur and realized that the vermiculite could become a source of economic wealth. The vermiculite had intriguing properties, the most striking of which were its properties of expanding enormously when heated and at the same time, assuming a golden or silvery luster. The expanded material floated on water and was almost as light as a cork. It appeared to have low heat conductivity and resisted high temperature; these features suggested that it could be useful for insulation.





“I was
real
fortunate
in being
able to
get a
job.”

People in Libby referred to the product as Zonolite and recounted its many intriguing properties. One resident enthusiastically noted that “you could grow a carrot and that carrot would be nice, long, and straight, just like a picture carrot.” Another one explained: “there were some experiments as far as making a diet supplement. Matter of fact, they even tried to make cookies, for people to eat. Some of the girls at the office ate those cookies. They made them up on the hill, like chocolate chip cookies!”



“I just
chose
the
wrong
place
to go
to
work.”

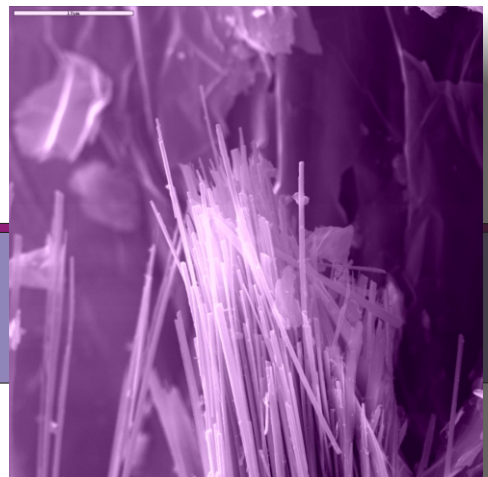
Mining operations began in 1919 and continued until 1991. Alley was right about the economic potential; at its height, the ore from this mine produced 80% of the vermiculite used worldwide. Vermiculite, however, was not the only substance derived from the mining operation. The geologic activity that created the vermiculite ore also created vast deposits of asbestos, a mix of tremolite and other kinds of asbestos. Initially, the asbestos seemed like an added benefit. Indeed, some mine workers described their jobs as quite exciting. Every day they looked for potential new products and uses for the asbestos.

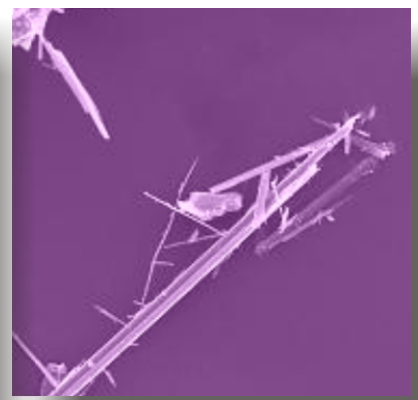
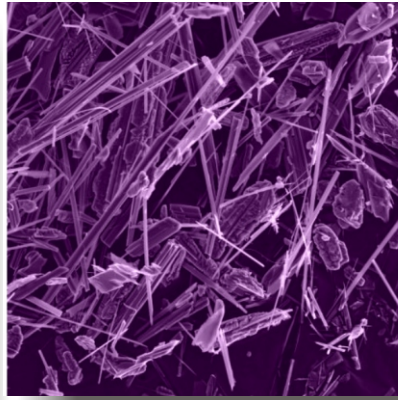
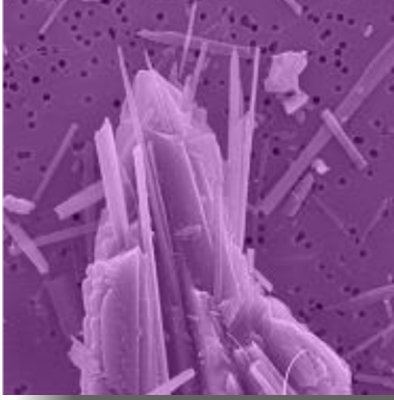
In many respects they were very successful. Asbestos proved to have highly desirable fire retardant properties. Thus it was used in hundreds of products including plaster and home insulation. It seemed virtually indestructible. Libby, a small mountain community in the West seemed to have found the key to a prosperous future.

“You
take
what
you can
get
when
you
need
the
money.”

What is asbestos?

Asbestos is a general term for a number of naturally occurring fibrous forms of several mineral silicates. Asbestos fibers can break off at the slightest provocation and can float in the air for hours or days; as a result, thousands of needle-like spears can be inhaled with each breath. These fibers most frequently lodge in the lungs and in the lining of the abdomen. Exposure to asbestos is related to increased levels of several types of cancer, one of which is mesothelioma. The fibers also cause asbestosis, a progressive and potentially fatal lung disease. Moreover, exposure to asbestos is associated with autoimmune responses and there may be a relationship between those responses and asbestos-related disease processes. There may be gene environment interactions that lead to increased susceptibility to disease for some people.





Dust and Fibers

In order to produce one ton of concentrated vermiculite, the mining operation in Libby had to move and crush fifteen thousand tons of ore each day. Thus the processing from the mining and milling operations produced five thousand pounds of dust and fibers, including asbestos fibers that blew over the community of Libby every day.

Until recent years, community residents did not understand the dangers posed by asbestos. In fact many miners thought that since the glittering substance in the vermiculite was called tremolite, it was not asbestos and so exposure posed no serious risk. They thought the dust they encountered at the mine was a “nuisance” and was “no worse than farm dust.” As one mine worker explained: “When you have a geologist and he is telling you that this dust is not a harmful dust, it is just a nuisance dust, and he is standing right beside you, breathing the same dust for eight hours, you kind of have a tendency to believe him. And we did. I believed them.” Nuisance dust seemed a small price to pay for a steady job that held the promise of a twenty-year retirement pension.

“We went from a “nuisance dust” to a “tremolite.”



“There was dust five or six inches deep on the rafters and every-thing.”

The mining operations provided community members with other benefits. WR Grace, the owner of the mine since 1963, allowed residents to pick up free truckloads of the vermiculite at the plant for use in home, garden, and civic projects. The asbestos-laden vermiculite was used in yards and gardens as fill or as a soil enhancer. It was used to pave driveways and sometimes in kitty litter boxes. It was used in public areas, creating the foundation for a boat ramp, ice rink, running track, baseball fields, and schoolyards. Children swung from ropes and landed in asbestos contaminated piles of vermiculite. A resident remembered: “Every kid who ever played little league here played on Zonolite.” It was used in children's sand boxes because it seemed “like a lighter fluffier kind of sand.”

Roads and train rails were covered with asbestos-laden dust as it was transported from the mine. People observed that “it dribbled from the railcars as they ran along the tracks.” The seedlings transplanted by the foresters were packed in asbestos-laden vermiculite. Asbestos-laden vermiculite was sprayed on the bushes and trees near the ball fields. It was used in shingles and roofs, and in the insulation of attics, walls, pipes, water heaters, and furnaces in homes throughout the community. As noted previously, it was even used as an ingredient in baked goods.



“If there aren’t jobs, people can't make a living.”

The Implications

Unfortunately, the community of Libby had ample reason to be concerned. Asbestos has been recognized as a dangerous substance for decades. In 1897, a Viennese physician noted that asbestos weavers and their families suffered from pulmonary diseases. In 1933, doctors working for Metropolitan Life Insurance found that 29% of workers in a John Manville plant had asbestosis. In 1942 confidential Owens Corning corporate memos referenced scores of examples of medical literature on asbestosis and the health risks of asbestos.

In the early 1940s, inspectors from the State of Montana noted the need to control the levels of “dust” at the mine and provide workers with respirators. By the 1950's, engineers for the Montana Health Department's Division of Disease control knew that the asbestos content contained in the dust of Libby's vermiculite plant could be as high as 27%. In 1969, an internal memo from Grace, the mine owner, documented a confidential study of Libby employees noting that 17% of the 1-5 years of service group have or are suspect of having lung disease and that there is a marked increase beginning with the 11th year of service (45%), climbing to 92% in the 21-25 years' service group.



“I was very proud to work for a company like W.R. Grace until 1979.”

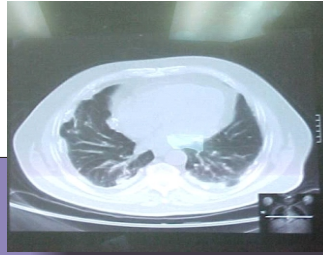
This information did not reach the workers or members of the community. Workers acknowledged the abundance of dust with explanations such as: “They've got dust up there that's a nuisance dust. It's not hazardous to your health. It's a nuisance dust. There are respirators there that you can wear if you want to, but it's not necessary because it's a nuisance dust....what most of us did is we just took a bandana and put it over our face and that way you could breathe...and forgot the respirators until they came up with a different quality of respirator [that would not clog].”

In 1999, the Seattle Post-Intelligencer uncovered the extent of the asbestos problem in Libby, Montana, when it reported that at least 192 people had died and an additional 375 people had been diagnosed with asbestos related disease. Initially the newspaper reports did not seem credible to the community or to the Environmental Protection Agency (EPA). Indeed, the EPA headquarters issued a statement claiming there was nothing in its files on Libby. Similarly, the National Institute of Occupational Safety and Health (OSHA) and the Mine Safety and Health Administration denied knowledge of a health problem.



“We never said it was going to be easy.”

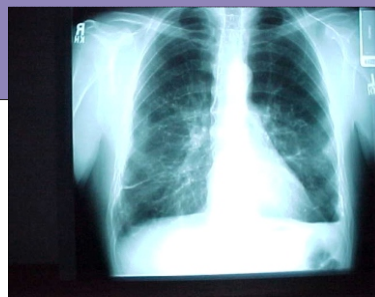
EPA



The state of Montana claimed there was no problem with asbestos. Even physicians in the community claimed they had no knowledge of people being harmed by asbestos. In fact, when the EPA initiated its investigation, as a follow-up to the alarming stories published by the Seattle PI, the activities were described by some in the agency as an “exit strategy,” a way to convince local residents that the health problems were not as serious as reported or perceived.

Health Effects

The contamination problem, however, was very real. Because more than 5,000 pounds of this asbestos-laden dust blew over the town every day, the contamination became a community-wide problem involving workers, their families and all Libby residents. Explained one resident, “you realized that the whole community had been exposed to this and were subject to the same fate as the workers were.”





“I have
asbestos
disease
although I
never
worked at
the mine.”

In 2002, the US Agency for Toxic Substances and Disease Registry (ATSDR) began conducting community-wide health screenings in Libby. Exposure to asbestos fibers among Libby-area workers and residents has now been conclusively linked to the development of asbestos-related diseases (ARD). These diseases include asbestosis, bronchogenic carcinoma, mesothelioma, and pleural plaque fibrosis of the pleural lining. Asbestosis is defined as bilateral diffuse interstitial fibrosis of the lungs due to inhalation of asbestos fibers. Pleural plaques, caused by scarring of the pleural lining, are indicative of asbestos exposure, but usually do not confer physiologic compromise.

Assessing the Risks

It is difficult to assess the full scope of health risks for a number of reasons. Asbestos illnesses typically have long latency periods (20-30 years). Increased numbers of reported exposure pathways increase the risk estimates. In Libby, EPA has currently identified at least 10 different exposure pathways. Asbestosis and mesothelioma are considered to be incurable at this time.



“EPA:
How
clean is
clean is
always
a major
issue.”

Preliminary findings from University of Montana research suggest that asbestos exposure is associated with autoimmune responses. In Libby, the risk for self-reported systemic autoimmune diseases such as lupus, scleroderma, and rheumatoid arthritis is higher than expected in a normal population. In addition gene-environmental interactions may play a significant role.

Asbestos: It may be closer than you think...

Unfortunately, the asbestos contamination extends far beyond Libby's city limits. More than a billion pounds of contaminated vermiculite ore were mined in Libby from 1960 to 1990. Shipping papers and invoices show that this ore was sent to 750 different addresses in North America. In addition, the ore was shipped to dozens of addresses overseas.





“Isn't our situation in Libby unique?”

Asbestos-contaminated vermiculite has been used in many products. The USGS reports that in 1998, more than \$300 million worth of asbestos products were exported or imported including pipes, construction materials, floor tiles, abrasives for cutting and grinding, and air craft and automotive brake parts. Asbestos has been used as a binding agent in thousands of building products such as cement, tile, mastics, and vinyl wall and floor tiles. Asbestos has been used in brake liners, drug store items like body powders, children's crayons, and in the Mono-Kote fire proofing that wrapped the World Trade towers.

A Painful Legacy

The historical use of asbestos and asbestos-contaminated products has created a painful legacy. Asbestos deaths in the US have skyrocketed since the late 1960s. Because of longstanding exposure to the substance, death rates are expected to keep climbing through the next decade. Findings of asbestos-related pleural effusions in 12 workers of a facility in Ohio have been linked to Libby vermiculite. In Minnesota deaths among workers at OM Scott and Sons Lawn Products have also been linked to contaminated vermiculite.





“Just in my family, four deaths, most of my adult family members have been diagnosed, many friends, many old classmates.”

The ATSDR has completed evaluations at 11 of 28 Grace plants that processed the largest amounts of contaminated ore from Libby. Assessors report that former workers, members of their families, and those living close to the plants had “most likely” been exposed to dangerous levels of asbestos and should be examined by physicians specializing in lung disease. Additional sites are currently being evaluated and similar findings are expected at those sites.

This manual has been created with such sites in mind. Perhaps lessons from Libby will prove helpful as other communities learn of their risk and the need for remediation.

“Under
the
Superfund
cleanup,
who
decides
what is
clean?”

Suggested Reading

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to asbestos.” *Am Rev Respir Dis* 134: 363-368.
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Notes

Chapter 2: Falling Apart

“I am concerned about EPA's priorities for sampling and cleanup activities.”



Libby is a hard working, blue collar community that is nestled in a valley of Montana's Cabinet Mountains. Bear, deer, elk, and moose wander through the meadows outside of town; sometimes they even wander the streets in town. The Kootenai River Falls, to the west of Libby, provided the scenery for Meryl Streep's movie *The River Wild*. The residents love the scenery, the traditions, and the friendliness of small town life. They feel blessed to live in a place of such incredible beauty. This is their home and for some families, it has been home for generations.

But the community does have its share of troubles. For generations, jobs in Libby and throughout Lincoln county were provided by the mining and timber industries. In recent years, jobs in these industries have decreased. The 2004 unemployment rate in Lincoln County is more than three times that of the Montana state average. According to the 2004 US Census report about half of the residents rank below 200% of poverty and one fifth are at or below 100% of poverty.



“Patience
is
needed
because
the
scientists
require
time to
decide
on a
lasting
solution.”

The 2004 median household income at \$26,754 is \$6,000 lower than that of the state. As in a number of other communities across the nation, many Libby residents fall through the cracks of existing support systems because they earn slightly more than the minimum income or fail to meet age requirements.

Many families depend on subsistence activities such as firewood gathering, hunting, wild plant and berry harvesting, or spot and seasonal labor. The importance of these subsistence activities should not be underestimated. As one resident noted: “the game warden we had was very lenient when it came to hunting out of season. If he saw a family needed it, he just looked the other way. Gardening was very important because it was a form of food.”

A national survey taken in 1998 found that 17% of Lincoln county residents were functioning at Level 1 of literacy; these individuals would be unable to understand and complete a job application or accurately read a label. In 2004, the Lincoln Health Department estimated that 14% of its population over 25 years held bachelors degrees, as compared to 24% in Montana as a whole.

On almost all health status indicators for 2004 including suicide, infant mortality, cancer rates, heart disease, motor vehicle accidents, and other traumatic injuries, Libby's rates exceed the state rates. In addition, Libby is designated as a Health Professional Shortage area and a medically underserved area.

So Libby already had a pretty full plate when newspapers began chronicling a story about its asbestos contamination. It took quite some time for community members to understand the scope of the contamination. There were a few advocates on the front line and they lobbied for intervention. But initially, few understood the levels of risk. Moreover, there were disagreements among city, state, and federal officials relative to how best to respond to the problems posed by contamination. It was not clear what “models” to use for making ultimate decisions.

Many of the demographic and socio-economic characteristics as well as the environmental challenges that are evidenced in Libby are shared by communities throughout the country. Indeed, in an article published April 12, 2007, the *LA Times* reported that in Los Angeles, 1.1 million Latinos, blacks and Asians live within two miles of hazardous waste sites. In that same article, EPA spokeswoman Jennifer Wood noted that the agency recognizes "that minority and/or low-income communities frequently may be disproportionately and adversely exposed to environmental harms and risks," and that the EPA attempts to address environmental justice concerns in its planning and budgeting.




“Who carries more weight, 50-60 businesses or 2,500-3,000 residents?”



New Information Brings New Fears

The residents of Libby were initially hesitant to believe that the contamination could be so serious and so widespread. These early stages of denial were followed by greater recognition of risk. But recognition came in stages and over a considerable period of time. Increased recognition brought a host of new problems. Residents were not sure who they could trust. It was not clear what abatement activities should be undertaken immediately, and what activities could be postponed. People worried about new exposure pathways and whether the community could ever again be safe for habitation. Government agencies, concerned about the potential for mass panic, questioned the amount of information that should be provided.

As residents learned about the scope of the contamination, they realized that what they had been told in the past about the mine and its health effects for the community could not be trusted. The “dust” was more than just “nuisance dust.” The numbers of residents who died or were sick were higher than previously realized. Residents began hearing new terms such as pleural plaques, interstitial disease, mesothelioma, sampling scenarios, and risk analysis.



“We need everyone to come together to find a solution which guarantees the health of future generations.”

Some residents faced decisions whether to participate in health screenings or undergo procedures like Bronchial Alveolar Lavage (BAL). Given the fact that asbestos-related diseases are incurable, some wondered about the wisdom of even seeking a diagnosis. Others were angry; they wanted to make sure that those responsible for this community disaster would be punished and they wanted financial compensation for the years of life that could be lost.

Believer vs. Non-believers

When environmental disasters occur, intense intra-community conflict is not an unusual by-product. Such conflict can tear apart the traditions of communality and civility that traditionally hold people together. This intra-community conflict can add additional and unexpected problems to an already difficult recovery process. There may be strong disagreement about what is most important. For example, should efforts focus on the healthy or on the sick, on prevention, or on care?

“I'm not sure if a medical health emergency declaration is needed.”

In Libby, the conflict seemed to deepen after the *Seattle PI* published a series of stories about the asbestos contamination in 1999. As one resident lamented: *“you can't imagine the chaos that that story caused right here in this little town!... Well, it turned neighbors against neighbors, friends against friends. This is not just BS; there are still some bad, bad feelings here, because of that. People would come out and defend W.R. Grace and criticize the people that were making claims against Grace. You can't imagine the things that were said about those people. The feelings. It was terrible. They forgot all about that people had died already. They forgot about the people that were dying and going to die. The only thing they thought about was that god-almighty dollar.”*

Depending on one's perspective, there may be strong disagreements about the allocation of resources. Whose home gets cleaned, whose illnesses get treated, and who pays for care? Who assumes leadership in the community, who is heard and who is ignored? As disagreements intensify, so too does a sense of isolation and dread. In addition, Libby residents frequently reported a sense of violation and a belief that theirs was the only community in the country to have experienced such a disaster.

“We've
lost a
lot of
the
tourism
dollars”

Libby's experiences are not unique. Communities find it very hard to overcome this level of discord. Environmental contaminations present long term problems and caring people can get “burned out.” Even when there are agreements about some aspects of a problem such as the need to reduce contamination, there may be fundamental disagreements about approach. Should efforts focus on “cleaning up” or “moving on;” should efforts focus on the rights of individuals or the needs of the community as a whole?

“There is still a social stigma, there are the two groups in town one who believes there's a problem and the other who thinks they are all a bunch of whiners.”

“We need closure, but we won't have it until the asbestos contamination is cleaned up.”

The range of perspectives from acceptance to frustration to denial and anger is shown by these resident statements:

- *“My first suggestion, when I first heard about this, was to do like they did with Love Canal: is to buy the town out, buy everybody out, let them get out of Libby, go where they want to go, and bury the town. Because I don't think they will ever be able to clean Libby up totally.”*
- *“There have been some articles in the newspaper, too, about W. R. Grace, saying that this finished product is relatively safe, you know. But most people don't believe that. It depends on what you want to believe.”*
- *“I know the real estate people are mad because they say that the price of real estate has went down because of the asbestos.”*
- *“Now, I've been asked a couple of times if you knew in 1979, why did you work until 1990? Well, I'd already been exposed for thirteen years. And the people, the geologist's record, the mill, the mine superintendents, the general managers, the executive officers, all would stand right beside you, eight hours a day, breathing that dust that you were breathing and telling you it was only a nuisance dust. Now, why in the hell wouldn't you believe them?”*
- *“Heaven's to Betsy, having a couple hundred pass away, I suppose I must have been aware of it to some extent.”*



While it is not always obvious, each group vies for its voice to be heard, for power, responsibility, and control. Thus each interest group brings a collection of needs, hopes, and expectations to the table. This struggle creates a community that on some levels has commonalities but also has deep divisions among classes, occupations, health levels, skills, expectations, and perspectives. No wonder some environmental contaminations have been described as slow motion disasters.



“Some people upon diagnosis start dying every day, like my father. But my mother began living everyday. ”

A Bigger Lens

Though each community has its own story about contamination, there is much that we can learn from one another. And while Libby residents have often echoed a sense of aloneness and abandonment, theirs is not the first or only community to face an environmental disaster. Indeed other communities throughout the country have lived through environmental calamities. Though the nature of their contamination is different, Libby and Centralia, Pennsylvania share a number of characteristics relative to geography and culture, custom and heritage, risk and response.

Centralia is also a mountain community; it is located in the northeastern United States, among the northern ranges of the Appalachian Mountains. Settled in the late 1850s and 1860s by immigrants, Centralia began as a coal mining town. By the latter part of the nineteenth century it had become a company town. The Lehigh Valley Coal Company was its dominant institution and agents of this New York-based firm made most of the important decisions in the community.



Like Libby, Centralia went through the socio-economic "boom" and "bust" cycles of the late nineteenth and early twentieth centuries. And like Libby, Centralia lacked a diverse economic base. When jobs in the coal industry decreased, new businesses were hesitant to locate in a place that was dependent on a declining, one-industry economy.

These socio-economic problems would be daunting for any community. But Centralia found itself facing even larger problems. In the early 1960s, an inextinguishable mine fire began to spread beneath the town. By early 1981, the fires were sending deadly gas into homes, forcing the government to install gas alarms.

As the fire intensified, residents faced some tough choices. The colliery and the mine formed the heart of the town. Some residents cherished the memories of good times and desperately wanted to stay. They believed that with time and effort, the fires could be extinguished. But other residents adamantly wanted to leave. They wanted to build new memories in a new and safer community.

“The CAG has been the best on-going support group for people to go to.”



There were, of course, some differences between these two communities. In Centralia, claims of direct health damage have not been proven; in Libby, hundreds of residents have become ill. In Centralia, no corporation has been held responsible; in Libby, WR Grace Corporation has been deemed responsible. Over the years, most of the 2000 residents who lived in Centralia have relocated; only a few scattered homes remain. Libby remains home to about 2,600 people and efforts to clean up the city and surrounding area are ongoing.

But Libby, Centralia, and countless other communities like Love Canal, Times Beach, and Tar Creek teach us that healing requires hard work, commitment, and ongoing dialogue. There are no quick or easy solutions.

Chapter 3: Picking up the pieces - Ethics: A Bridge for Informed Decisionmaking

“You
have to
catch
people
on their
own
ground.”

As indicated in the Preface, the E-ABCs project tried to find ways to translate scientific information so that residents in an environmentally contaminated community could make informed decisions about their health and well-being. The discipline of ethics seemed to offer a useful framework for that endeavor. Ethics has traditionally focused on our beliefs about obligations and how one should behave, about our standards for assessing good and bad, fair or unfair. When used within the realm of healthcare, ethics addresses issues such as respect for persons including the intent to do good, avoid harm, protect autonomy, and pursue justice. All of these issues are relevant when trying to make informed decisions about one's health.

But ethical concepts and the processes can seem quite academic. And, in fact, ethics is often approached as an academic endeavor. While there are countless courses, books, journals, and academic centers devoted to ethics, the audience is typically academic or at least highly professional. Efforts to engage the greater society have often been limited to specific activities such as a series of community workshops, courses at a community college, or newspaper articles.



“We're
all going
to have
to make
changes.
Change
is a part
of life.”

These approaches may be helpful but they may appeal to a fairly limited audience. They may not necessarily support ongoing dialogue in a community. Moreover, when a community experiences an environmental disaster, residents may look at their situation through a unique lens. In Libby, for example, much attention has focused on obtaining financial compensation for the suffering and illnesses that people have experienced. Many feel they have been victimized and minimized by a ruthless system that clearly knew about the risks. Some residents want financial compensation so they can obtain healthcare. Others want financial compensation so they can more fully enjoy the final years of their lives or leave a legacy for their children.

These human reactions to grief, deception, and loss are further complicated by systemic obstacles. For example, people do not have equal access to healthcare. Since obtaining treatment can be difficult, an ethical principle like autonomy can become a very theoretical construct. Does one really have access? Does one really have choices? An environmental disaster does not unfold according to ethical principles and solutions may seem unfair.

“I am not going to cry on anybody's shoulder.”

The values, beliefs, and emotions when coupled with the systemic obstacles bring special challenges to an ethics project. It has to be structured to encourage the participation of diverse constituencies, many with no previous exposure to ethics as a discipline. Obviously the project has to be practical as opposed to academic and guided by realistic goals relative to what can be achieved.

It may be helpful to remember that ethics involves doing the right thing. Even in a seriously damaged community, meaningful activities can be pursued. At a minimum, people can be empowered to seek greater justice, to see a broader world, to make informed decisions, and to build coping skills so they can work toward a common goal.

Shared Voices and Shared Visions

We all want to live in healthy communities. We want to create healthy and loving families that feel safe and secure. In short, we share many basic ethical beliefs about the importance of beneficence or doing what is best for one another, avoiding causing intentional harm, being fair, and respecting a person's right to make one's own decisions.

We may not describe these beliefs as *ethical principles*, but we may recognize them as part of our belief system. We may think of them in terms of how we should treat one another. When are we asked what we do or how we should act, it is often within this practical framework of *who does what to whom and how*.



“I'll go to the bowling alley and have a drink and everything will be alright.”



We may find it harder to agree, however, about how best to *achieve* the visions we so value. And so, regardless of whether a community's problems are caused by asbestos, emissions from oil refineries, or pesticides from farming, disagreements can arise and relationships can be damaged. Persons who are ill due to the contamination may want information that addresses health issues. Business owners may perceive that a focus on illness creates an unhealthy business climate and would rather allocate resources to economic development. The just allocation of resources is never easy especially when resources are scarce. There can be as many different angles of vision as there are residents!

Our experiences in Libby remind us that people who hold one angle of vision do not necessarily speak easily with those who hold a different view. Any community is a bit like the group of people who, with blindfolds tightly in place, are told to describe an elephant. One person may describe large feet, another may describe a large trunk, or a small tail, or floppy ears, or rough skin. Nobody can quite imagine what the elephant really looks like.

“We will have to deal with this probably for another 30-40 years- there won't be any quick fix.”

Libby has now been a Super Fund site for a number of years. Some residents believe that the community is seriously contaminated and will never be safe. But other residents question the extent and the severity of the environmental contamination. They believe the asbestos can be removed and the community will be safe. Some residents are very vocal about their perspectives; others remain silent. Libby shows us that even when there is some agreement among various constituencies about the occurrence of an environmental contamination there may be great disagreement about the level of risk, how one should respond, who should be held responsible, who should provide the clean-up, and who should receive assistance.

Anticipating Obstacles

Our experiences in Libby taught us that a community ethics project needed to overcome some sizable barriers.

Dialogue in Libby was compromised by issues that include:

- ***Culture of silence:*** For years, there was a culture of silence and deception in Libby. Many miners thought that the vermiculite they mined was contaminated only with tremolite; they did not realize that tremolite was a type of asbestos. Many miners thought that the chest X-ray program, initiated by the company, was created to make sure the miners stayed healthy; they did not realize that the company was monitoring lung abnormalities. The historic lack of disclosure or transparency inhibited the willingness of some community members to trust new information.

“Something is wrong with this picture. W.R. Grace is willing to pay 100% of autopsy costs, but not 100% of medical costs.”

- ***Vulnerable populations:*** It can be hard to accommodate the needs of people with less education, power, or connectedness. Some populations can find it hard to focus on theoretical principles of ethical decision making and processes for informed consent when they are more concerned with “staying alive” and “keeping food on the table.”
- ***Disclosure of scientific findings:*** Ongoing disclosure can be hampered by the fear of causing panic, controversy, ugliness, or discord. Disclosure is particularly problematic when there are disagreements about fundamental issues such as appropriate models for risk analysis or abatement.
- ***Access to resources:*** Communities may not have access to needed resources including resources such as ethicists or mediators who are willing and able to tackle a community-wide initiative.
- ***Academic orientation of ethics:*** Residents may question how an ethics project could help an environmentally damaged community. Concerted efforts must be made to develop practical and accessible approaches.
- ***Information flow:*** Adequate dissemination of information and resources can be constrained by various structures. At different times, information in Libby was controlled by the company, the state, the EPA, even the local newspaper. It can be challenging to know how to obtain unbiased and scientifically accurate information so that one can make informed decisions.

Ethics can help

- Achieve dialogue
- Make good decisions
- Make room at the table
- Find common ground
- Explore perspectives
- Use good processes

“The Superfund law does not require EPA to do a complete cleanup, only to make an improvement.”

Doing the Right Things

Our experiences in Libby underscored the need to develop practical approaches that encourage ongoing dialogue and sustained reflection. Both dialogue and reflection are at the heart of ethics and ethical decisionmaking. The quantum physicist, David Bohm notes that the original meaning of dialogue was “passing or moving through...a free flow of meaning between people in the sense of a stream that flows between two banks.”

True dialogue occurs when:

- People feel that they can be honest and truthful;
- They listen to others and feel that others are listening to them;
- All opinions and ideas are given the same space and respect;
- Residents broaden their perspectives and awareness of competing moral solutions.



“I even know healthcare providers who have opted not to be screened, they felt you can't fix it then I don't want to know.”

The practical connections between ethics and dialogue may not be immediately obvious, but true dialogue reflects basic ethical principles. It is honest, inclusive, and respectful. Such dialogue, however, is difficult to achieve in any community, especially in an environmentally contaminated one. Dialogue is time consuming; there will be mis-steps, mistakes, progress, and backsliding. For example, the E-ABCs project made a commitment to translate scientific information as accurately as possible.

But residents did not uniformly welcome such information, especially in cases when neither cure nor remediation was possible. At times, dissemination of information seemed to heighten anxiety or anger. We learned that the timing of disclosure, the process, and supporting documentation - who does what to whom and how and under what circumstances - became matters of primary concern. Even when dissemination is very carefully planned, an optimal outcome cannot be guaranteed. So it becomes imperative to create an on-going, recursive processes that can help sustain dialogue, reflection, and more dialogue.

Reflection can help residents:

- Appreciate the moral basis for human behavior
- Appreciate the value of well reasoned judgments
- Recognize personal motives and relate them to universal ethical principles
- Integrate experiences in ways that support enduring understandings

Reflection is important because people are not always aware of the motives behind their reactions. A considerable body of literature, for example, suggests that human beings are poor predictors of emotion. We think we will react one way, and are quite astounded when we react an entirely different way. In theory most people like the ideas of openness, fairness, and honesty. But those values may be less appreciated if they result in diminished resources or are perceived as counter to one's personal endeavors or needs.

“The complaints that people have made in meetings reflect anger in the community.”

Thus efforts to promote dialogue have to be accompanied by strategies and decisionmaking models that also promote reflection. Through dialogue and reflection, communities may find that it is possible to create some shared visions and shared values. Residents may still be unclear about the connection between ethics and practical actions but may be able to agree on some foundational principles such as:

- Decisions about the health of a community should be as impartial as possible and not favor friends, family members, or close associates. Decisions are not usually well accepted if people believe that only certain people will benefit.
- Rules and decisions must be publicly known and publicly justified. If decisions are not publicly known, they may be viewed with suspicion.
- Opportunities will be created so that people can participate in the decision making process. If decisions seem unfair, they can be contested or disputed. By creating opportunities for participation, new information can be brought forward. New information may ultimately allow us to make better decisions.

“Workers who had high exposures, homes with contaminated vermiculite insulation, and schools should have the highest priorities for action.”



“I know of some people who went through the screening but never opened the envelope to see the results.”

From Theory to Practice

The need for reflection and dialogue can be appreciated when facing an ethics-related issue such as a health screening. On the surface, a health screening seems like an appropriate response when faced with an environmental contamination. Indeed, the ATSDR initiated a health screening in Libby so that the health effects of the asbestos contamination could be verified. Screening criteria were established. Eligibility was based on factors such as: employment in the mine, years of residency in the community, and sharing a household with mine worker. Residents who met the screening criteria were encouraged to participate in activities that included chest X-rays and other protocols. Once residents are 18 years of age and meet the other criteria, they become eligible for screening.

A health screening, however, can raise some complicated ethical issues such as:

- What is at stake in the situation?
- What is at stake in alternative courses of action?
- Who are the critical stakeholders?
- How can we understand and balance the conflicting moral obligations?

“Yes
mainly
they
thought
there
was
nothing
to be
done
about
it.”

A stakeholder is *anyone* who might be affected by the decision. The following quotes express the difficulties that Libby residents faced when deciding whether they should participate in screening or not:

- Fear of knowing, even within my own family. I am one of six, four have been screened and three have been diagnosed. The other two don't want to know.
- I never worked there, there's nothing they can do about it anyway.
- Oh I'm going to die anyway so I may as well just hang it up and not try to do anything about it.
- They didn't get screened because they felt they may at some point in time have to relocate to find work.
- For a long, long time people were very hesitant about telling anyone they had been diagnosed or even if they just showed abnormalities.
- I know of some people who went through the screening but never opened the envelope to see the results.
- They didn't want to know...they say in 20-30 years it won't even matter.
- I even know healthcare providers who have opted not to be screened, they felt you can't fix it then I don't want to know.
- There is still a social stigma there are the two groups in town one who believes there's a problem and the other who thinks they are all a bunch of whiners.

“Some people perceive that “non-detect” means safe; that is not necessarily the case.”

Given the fears, the denial, and the consequences associated with screening, the ethical analysis includes consideration of the costs and benefits of an action for each stakeholder as well as the nature of the relationships with and among stakeholders. With questions of genetics, for example, the analysis may even include distant relatives or future generations.

Genetic testing or screening is deemed most appropriate when early treatment or other modifiable risk factors allow for behavior change or preventive interventions that can reduce the probability of harm, and when an assessment of the benefits, harms, and costs of testing and population screening programs provides the basis for the public health policy. Based on the importance of identifying risk factors, pursuing preventive interventions, and informing public health policy, the plan to screen Libby residents seems reasonable.





But a health screening for asbestos-related diseases can also raise challenging issues. There is currently no cure for asbestos-related diseases. Thus screening can raise issues such as:

- The difficulty of assessing the results of tests and providing helpful information about risks;
- The potential psychological harm to individuals, family members, and family interactions and relationships that may result from testing, inaccurate or misunderstood results;
- The potential misuse of risk information in insurance and employment discrimination; and
- The appropriate role for government regulation of commercial tests with uncertain predictive accuracy.

“Now that there is more medical support available they are getting more and more curious about it.”



“A big one is loss of ability to participate in activities.”

Ideally, screening may encourage persons to pursue preventive activities. Persons with asbestos-related diseases, for example, are encouraged to make lifestyle changes such as smoking cessation and weight loss. But people may not be willing to change behaviors. In fact, there is evidence that the stress created by genetic information can actually *lessen* the likelihood that the individual will monitor himself or herself for early signs of the disease.

It is not clear how, for instance, a screening result that shows uncertain clinical findings such as “pleural lung changes” might affect the decisionmaking of an 18 year old. We did learn in Libby, for example, that residents frequently interpreted a screening result as a diagnosis. Potential harms may also arise from the misinterpretation of a negative test result, including a false sense of security.

Practical Strategies

The kinds of ethical issues that accompany a plan to offer screening underscore the need to develop supportive interventions and services. Residents will need assistance with the ethical issues that accompany:

- ***Informed consent:*** ability to make a decision, provision of relevant information, and assurance of voluntary participation.
- ***Surrogate decisionmaking:*** when patients lack decisionmaking capacity, others must make needed decisions on their behalf.
- ***Privacy and confidentiality:*** privacy entails the right of patients to control access to their physical bodies and personal information. Confidentiality entails how information should be shared for the purpose of providing healthcare.
- ***Resource allocation:*** fair distribution of goods and services
- ***Negotiating differences in perspective:*** responsibility to educate patients about the range of options, including differences in perspectives so that patients can make treatment choices
- ***Risk assessment:*** explanation of the models and processes used to determine exposure.

In order to accommodate this range of concerns, it is important to develop materials that are as accurate and accessible as possible. Patients need to understand their rights and options, including processes for supportive decisionmaking. Screeners have to anticipate potential issues such as family coercion or pressure to participate in a screening and develop measures or materials that address such issues.



“Fear of knowing, even within my own family, I am one of six four have been screened and three of us have been diagnosed. The other two simply don't want to know.”

Topics for Discussion

Regardless of the kinds of environmental contamination, the following topics may help promote dialogue and reflection, and provide opportunities for community residents to share their different perspectives:

- Discuss how the terms “ethics” and “morality” relate to events in your community.
- Identify common sources of moral guidance or authority such as the Bible, other religious texts, lessons from history, community standards, professional codes, and family traditions.
- What are our deeply held beliefs?
- What are the assumptions from which we're operating?
- What are our mental images of what's going on and being considered, and where did those images come from?
- How are we expressing those mental images?
- What is happening inside us as well as in the team or group?
- Are we even looking at the same data?
- Are we thinking in the moment or from memory or projection?
- Are we really listening and hearing what others are saying?

“Get involved and work together and put aside some of our own personal issues.”

Chapter 4

Focus: Doing Research in an Ethical Fashion

When researchers come to town

Important information can be obtained when well designed research studies are conducted in environmentally contaminated communities. Such a community offers scientists and researchers an opportunity to study a number of disease states, risk factors, and potential interventions. Biomedical research studies, offer researchers opportunities for socio-behavioral, economic, journalistic, and historic research.

Before participating in research studies, however, an environmentally contaminated community needs to clearly understand the research agenda and give careful consideration to the fair distribution of any benefits and burdens associated with the research. It is important to understand that research may be conducted for many reasons and without adequate scrutiny research can potentially extend rather than reduce harm.

“The best we can hope for are people who are willing to research avenues for us to help ourselves.”

“We need to get back on a more positive and substantive track, identifying and helping to solve problems important to the community.”



When considering participation in research studies, regardless of the methodology that will be employed (Community-based Participatory Research (CBPR), clinical trials, or other approaches), a number of issues require thorough analysis. Successful research partnerships delineate roles, responsibilities, and expectations of all who are involved. Attention is given to issues such as fair distribution of any benefits and burdens associated with the research. It is important to explore the goals of the research so that community members have realistic expectations about the results of the research. In order to honor protocols for informed consent, potential participants need to understand not only the purpose, procedures, risks, and benefits of participation-including, importantly, the possibility of no benefit-but also alternatives to participation. Because it is hard to merge the world of research and the world of the community, it is important to clarify how results of studies will be used, how data will be shared, how the community will stay informed, and how conflicts can be resolved.

“A lot of people know how they don't want to die.”

Why Problems Can Develop

When designing research studies it is important to recognize, and accommodate to the greatest extent possible, the competing interests of all who may be involved: researchers, community research partners, industries, research participants, and the general public. For example, today's researchers may receive benefits such as tenure track positions, publications in peer reviewed journals, lucrative financial rewards like patents and speaking engagements, and membership on scientific committees. They can also receive less tangible benefits like esteem, fame, and status in the research community.

Community research partners may receive similar benefits. Research dollars can support positions, publications, and other financial awards. Like the researcher, the community partners can also receive less tangible benefits, such as esteem, fame, and status in the local as well as national community. The local institutions and industries may reap considerable benefits in terms of indirect resources and profits.

Local residents who participate in research studies may receive special access to treatments or other incentives. Finally, the general public may receive benefits in the form of treatments or cures. Given these multi-layered interests, complex issues associated with disclosure and reciprocity, benefits and burdens, risks and rewards can be overlooked and so ethically compromise the research agenda.

“People are proud and want to handle things themselves.”

Anticipating risks and rewards

Two recent legal cases show the kinds of issues that can arise when conducting research that involves human beings. In the first case, *Moore v. Regents of the University of California*, Mr. Moore was not fully aware of the fact that the physician treating him was also a researcher. During the diagnosis and treatment phase, the physician extracted Mr. Moore's spleen, blood, bone marrow, and other tissue samples, using them to create a patented cell line.

Moore *was* seeking treatment for his condition *and* he agreed to the recommended procedures. But Mr. Moore was not told that his samples were being used for research. Upon learning that the samples from his body led to substantial profits for the physician/researcher as well as the university, he filed suit, arguing that he should receive some of the proceeds from the patent.

In 1990, the California Supreme Court held that a physician's duty includes a fiduciary duty to disclose to the patient information that is material to the patient's decision such as information about the potential economic or research value of body tissues that are removed. The Court also held, however, that the actions of the physician and the University did not constitute an unlawful taking under California law.

“Even though a patient dies of extreme mesothelioma, people still say oh well she smoked.”

The requirement to inform did not include a requirement for any compensation or participation in the profit sharing. In reaching this decision, the Court expressed concern that extending the law of conversion in this way would "hinder research by restricting access to the necessary raw materials," and "threatens to destroy the economic incentive to conduct important medical research." This case teaches us the importance of honoring the consent process and disclosing to the greatest extent possible potential benefits.

Problems associated with full disclosure and the expectations of the research agenda were at play when Dan and Debbie Greenberg and other families filed a suit in 2000 against Miami Children's Hospital. The Greenbergs had two children afflicted by Canavan disease, a rare but fatal genetic disorder. They found a physician/researcher who was willing to conduct research on this rare disease and provided him with tissue samples from their children. They also encouraged other families to participate in the research and they raised funds for the scientist's research. The research was very successful and a gene patent was awarded to the hospital where the physician/researcher was conducting his research.

The Greenbergs, however, had not been informed that a patent was being sought and were shocked when they found that the hospital was using licensing agreements to restrict disease testing and was obtaining royalty payments from the centers licensed to conduct the testing. The Greenbergs sued, alleging, among other things, breach of fiduciary duty and unjust enrichment. The federal district court dismissed all the Greenberg's claims with the exception of the claim of unjust enrichment. The parties settled this remaining claim under an agreement that allowed those seeking a cure for Canavan to conduct research without paying royalties.



The outcome of these two cases is still a matter of considerable discussion. Several patient advocacy groups contend that the rulings were unfair and are currently proposing a more equitable relationship between those participating in research studies and those conducting them.

Protecting the Public

The families who participated in the Greenberg study desperately wanted a cure for a fatal disease. People who lived in environmentally damaged communities can experience the same kind of desperation. They may suffer from diseases for which there are currently no cures. They may fear that their children or other relatives will experience those diseases. Many people in Libby, for example, live in fear and anxiety for years because asbestos-related diseases have long latency periods.

This fear and anxiety coupled with the socio-economic risk factors detailed in the previous chapter, create a very vulnerable population. In some respects, the vulnerabilities are similar to those experienced by persons who participated in the historic Tuskegee study.

Tuskegee was designed to study the course of syphilis in the African American population. A nurse who was a trusted member of this Alabama community was hired to coordinate the enrollment of poor African American males. Those who were enrolled did not understand the disease nor did they comprehend the full purpose of the study.

The participants in the Tuskegee study received numerous benefits such as free meals when visiting the clinic and burial stipends. The illusion of treatment was carefully perpetuated by the researchers. Once effective treatment became available, it was not offered to the participants.

Obviously there are differences between the participants in the Tuskegee study and the residents of a community like Libby. Moreover, different protocols, such as the Common Rule, are now in place. These protocols ostensibly prevent ethical violations. Still, it takes considerable ethical reflection to anticipate and then address the range of issues that can lead to exploitation.

For example, when asked to participate in studies, vulnerable populations may agree to do so with an altruistic intention that “good will come of it,” without fully understanding the actual purpose or limitations of the study. Or, they may participate because they trust a recommendation or suggestion made by their healthcare provider, or because they equate participation in a study with optimal treatment. While trusting one's healthcare provider is critical for the healing process, trust without adequate understanding can threaten the ethical integrity of research.



“Even the people that are directly affected sometimes don't get the story right when they tell someone else.”



“For a long, long time people were very hesitant about telling anyone they had been diagnosed.”

In Libby, people often expressed a belief that research would “put us on the map” and “bring prestige and meaning to the community.” People also thought it would “bring a cure.” Because the research environment is unfamiliar to most community members, residents may have a limited idea of what the study may actually involve. Because they may not fully understand the research environment, they may simply trust those who invite them to participate in studies. They may not see the need to carefully read the informed consent forms before agreeing to participate. Even if they read the forms, it may still be difficult to understand what is truly involved when participating in a research study.

Other conditions or features of the environment may raise ethical flags. In rural communities, for example, residents may know one another and have multiple relationships with those conducting the studies; these dual relationships can make it hard for potential research participants to refuse to participate in studies. Similar to the Moore case, the healthcare provider may also be a researcher. A patient may fear a loss of care if rejecting the offer to participate in a study.



Patients may also confuse participation in a research study with treatment for their condition. Research is designed to generate scientific information for a population rather than individual information or care. When potential participants do not understand key research concepts, they may labor under a “therapeutic misconception” that leads them to believe that participating in a medical study would provide access to better treatments or diagnoses. Our pilot work suggests that misconceptions occur, in part, because many patients trust that their physicians would not recommend participation in a clinical trial unless it was the best course of treatment for them individually. This conflation of research with treatment represents a form of the “therapeutic misconception” that has not been well studied.

Community members may not realize the value of their contributions especially since contributions can come in such different forms as blood, samples, tissue, as well as stories, ideas, opinions, and attitudes. It can be particularly hard for participants to understand statements about risks, benefits and disclosure of possible conflicts of interest, while these are generally accepted as key parts of the informed consent process each issue is in and of itself complex and requires serious consideration.

“As a community, we need to decide how we are going to address this.”

Elements of Informed Consent

Informed consent requires that an individual truly understands and freely makes a decision to participate in a study or treatment. Researchers should be prepared to:

- Explain in clear and succinct language exactly what will be done;
- Explain the range of benefits and burdens for both the researchers and the participants;
- Encourage the participant to ask questions and seek advice from others if necessary;
- Create opportunities for questions and dialogue;
- Clarify the participant's expectations;
- Assess the participant's decisional capacity;
- Avoid pressuring the participant for a quick decision. Allow enough time for the participant to fully evaluate the information in the consent form and a decision about participating;
- Provide verbal and written materials that explain all key aspects of the research;
- Allow the participant to discuss preferences and fears;
- Provide participants with contact information for the researchers;
- Provide participants with contact information for the IRB chair in case a person is not comfortable contacting the researchers;
- Establish protocols for sharing results from the study;
- Maintain an absolute commitment to the wellbeing of the participant;
- Monitor one's own actions and motivations.

“Almost daily we hear about people who have to make a choice of getting their medication or putting food on the table.”



“I do think people aren't getting all the facts.”

In order to honor the elements of the informed consent process, researchers and community research partners may need to consider options such as the use of independent advisors who can help potential subjects make decisions about participation in research trials. For some studies, it may also be wise to offer a grace period so potential participants can, without coercion, think about their participation. Regularly scheduled phone calls to community partners, prompt sharing of early findings, participation in community events, and use of novel ways to share information and even potential profits with all those involved may help. Extra efforts should be taken when a healthcare provider is also a researcher. Without firewalls that separate research and clinical care, a patient's autonomy can be easily violated.

Sample Disclosures

It can be challenging to translate the key elements of informed consent into a workable protocol. For example, in order to conduct research in an ethically sensitive manner, researchers need to clearly discuss any potential conflicts of interest. The disclosure statements on informed consent forms have generally been vague. National guidelines are evolving and a recent effort to develop model language for disclosure is discussed in the following article : Weinfurt, KP, et al: Developing model language for disclosing financial interests to potential clinical research participants. IRB: Ethics and Human Research, 29(1):1-5, 2007. Disclosure statements based on the recommendations in this article appear below.



Generic Disclosure

The researcher, Dr. XX, leading this medical research study, might benefit financially from this study. The possibility of financial benefit has been reviewed by an Institutional Review Board. The Board thinks that the financial benefits are not likely to affect your safety or the scientific quality of the study. If you would like more information, please ask the researchers or the study coordinator.

Specific Disclosure

The person leading this medical research study, Dr. XX, might benefit financially from this study. Specifically, [insert appropriate description from below for salary support or other compensation]. The possibility of financial benefit has been reviewed by an Institutional Review Board. The Board thinks that the financial benefits are not likely to affect your safety or the scientific quality of the study. If you would like more information, please ask the researchers or the study coordinator.

Salary Support

Company XYZ is paying some or all of the salary for the doctors and staff who are working on this research study.

Money Received Outside of the Study

This research study is supported by money from Company XYZ. In addition, the person leading this research study receives extra money from Company XYZ for work that is not a part of this study. These activities may include consulting, advisory boards, giving speeches, or writing reports. The person running this research might receive hundreds or thousands of dollars for this work.

Per Capita Payments

Company XYZ pays the hospital/clinic running this research study for study supplies, staff salaries, and for each person who agrees to participate in the study. This amount of money is just enough to cover the cost of running the study.

Finders' Fees Restricted to Research Uses

Company XYZ pays the hospital/clinic running this research study enough money for study supplies, staff salaries, and for each person who agrees to participate in the study, plus some extra money. The person running this research study can use this extra money for other work-related costs, such as travel to meetings, paying support staff, purchasing new office equipment, or funding other research.

Unrestricted Finders' Fees

[Note: Substitute this entire paragraph for the "specific disclosure" language given above.]

Your doctor might benefit financially from this medical research study. Company XYZ paid your doctor \$XXXX for referring you to this research study. Your doctor can use this money however he or she wishes. The possibility of financial benefit has been reviewed by an Institutional Review Board. The Board thinks that the financial benefits are not likely to affect your safety or the scientific quality of the study. If you would like more information, please ask the researchers or the study coordinator.

Researcher Holds a Patent

The person leading this medical research study owns [or has applied for] a patent on the new [test, drug, treatment] being studied. Research studies like the one you are thinking about joining are done to determine whether the new [test, drug, treatment] is safe and effective. If research shows the new [test, drug, treatment] is safe and effective, the person leading this study would receive a part of the profits from any sales of this [test, drug, treatment].

University Holds a Patent

Research studies like the one you are thinking about joining are done to determine whether the new [test, drug, treatment] is safe and effective. ABC University owns [or has applied for] a patent on the new [test, drug, treatment] being studied. If research shows the new [test, drug, treatment] is safe and effective, ABC University would receive a part of the profits from any sales of this [test, drug, treatment].

Researcher Owns Equity

This research study is designed to test a product made by Company XYZ. The person running this study has an investment in Company XYZ, such as stock. The amount of money the investment is worth might be affected by the results of this study. This means that the person running this study could gain or lose money depending on the results of this study.

University Owns Equity

This research study is designed to test a product made by Company XYZ. ABC University has an investment in Company XYZ, such as stock. The financial value of this investment might be affected by the results of this study. This means that ABC University could gain or lose money depending on the results of this study.

Chapter 5: Engaging Healthcare Providers in Ethical Discourse

Ethics, Healthcare, and the Environment

When environmental disasters occur, the ethical responsibilities and obligations of healthcare providers become more complicated.

Healthcare providers have traditionally focused on the needs of individual patients. In a contaminated community the individual needs may increase as patients suffer from health effects from the exposure. As healthcare providers tend to those individual needs they also will be asked to respond to the collective health-related problems that burden their communities. In addition to advocating for the well-being of their patients, they may be asked to investigate patterns of disease and provide solutions that relieve risk or burden throughout the community. They may be called to consider the just distribution of community-wide health benefits. They may be asked to develop and interpret new policies and even oversee research studies.

“As long as it doesn't come under the heading of therapy or counseling; people here are very resistant to that.”



These new demands call for an approach that can address community needs in the most inclusive way possible. Such an approach draws significantly, not only on ethical principles, but on the public health perspective as well. The foundation of both ethics and public health focuses on social justice and fairness in the distribution of benefits and burdens. Both use interdisciplinary approaches and methods; public health emphasizes the need to implement preventive strategies as well.

While healthcare providers in a contaminated community may be willing to accept expanded roles, they may not have the training or expertise required for such a task. Even when healthcare providers have received formal training in public health or health ethics, many feel that applying the theoretical knowledge in real life situations is difficult. Most rural healthcare providers, for example, report that they have not received any training in healthcare ethics or bioethics, and lack access to appropriate resources.

“They even get angry at us for diagnosing them.”

A Very Brief History of Bioethics

Bioethics has been described as the study of the moral principles and values that accompany medical treatment and research. The field has historic connections to ancient Greek medicine, medieval Christian medicine and traditional moral philosophy. It is also, however, is also a new enterprise, one created in response to an array of issues like the technological problems posed by modern medicine and rights of self determination for patients.

Within the healthcare setting bioethics has focused heavily on the ethical aspects of clinical care provided to individual patients. To a considerable extent ethical deliberation has focused on end-of-life care and the allocation of services.

Models like ethics committees and case consultation were developed to help healthcare providers and families solve ethics-related problems that develop within the institutional setting. Although these models have been helpful within the hospital setting, their applicability when dealing with community-level problems has been limited.

Our studies show that many healthcare providers have had either very limited, or no, formal training in ethics. Healthcare providers also report that they lack access to practical ethics-related resources. These constraints can hinder the ability of healthcare providers to respond to the kinds of community-wide health ethics dilemmas that occur in environmentally contaminated communities.

The information in this section is designed to help healthcare providers overcome those constraints. It draws on a significant body of research conducted by the authors over a 10-year period of time and across multiple states.

“People are aware that certain families get hit more than others.”



Key Ethical Concepts:

An environmental disaster requires that healthcare providers thoroughly consider a very fundamental question: Who does what to whom and how and under what conditions? In order to respond to this question healthcare providers need to:

- Develop critical thinking skills for evaluating competing moral claims, arguments and goals that are frequently encountered in healthcare practice;
- Reflect on the responsibilities of healthcare providers to help develop and implement social policies that influence health care delivery;
- Understand clinical competencies including professional responsibility, patient rights, privacy and confidentiality, truth telling, distributive justice, and research ethics;
- Identify moral, economic and social issues that impact community health care;
- Reflect on the moral and professional obligations of healthcare providers to colleagues, healthcare practitioners and patients.

“Some people are scared to move here.”



This is a challenging agenda. When we talk about responsibilities, obligations, and claims we often use words like morals and values and ethics. Often these words are used as interchangeable terms associated with right or wrong, good or bad, fair or unfair.

Moral refers to beliefs about obligations and how one should behave, about our standards of good and bad.

Values are the names for conditions that represent what is right and that further human good.

Moral values are beliefs we prize and promote.

Ethics is the systematic study of morality, the study of who does what to whom and how and to what effect.

Ethical dilemmas often involve choices between highly valued but competing goals, between collective good and the rights of individuals.

“We need to be able to develop the trust with the EPA that our concerns will be satisfied.”

These concepts have often been used to address ethical issues faced by individual patients and their families. Within this framework, healthcare providers are expected to seek the best care possible for each patient and to avoid causing any harm. Healthcare providers are expected to be fair and just when providing services. Evidence of autonomy or respect for persons is often linked to a protective function. Healthcare providers are expected to make efforts to give the patient sufficient information about health status and support the full participation by the patient in decision making.

Moving From Care of the Individual to Care of the Community

When the role of healthcare providers expands and becomes more community-oriented new ethical and public health obligations emerge. Bernard Turnock, author of the text book *Public health: What it is and how it works*, defines public health as “a broad social enterprise, more akin to a movement, that seeks to extend the benefits of current knowledge in ways that will have the maximum impact on the health status of a population. It does so by identifying problems that call for collective action to protect, promote, and improve health, primarily through preventive strategies.”

“The locals are proud and want to handle things themselves.”

“Some think that only the people who smoke cigarettes will get it.”

He notes that public health is unique in its interdisciplinary approach and methods, its emphasis on preventive strategies, its linkage with government and political decision making, and its dynamic adaptation to new problems placed on its agenda. Turnock identifies key elements of the public health agenda including:

- The health of the public - our success at curbing infectious diseases (diphtheria, polio) and our less-successful efforts to eliminate chronic disorders (cancer, diabetes, depression), and to foster good health through exercise, nutrition, decent workplaces and friendly neighborhoods.
- The professionals who staff public health departments who offer flu vaccines, make sure restaurants meet minimum health standards, try to minimize lead poisoning among children, staff clinics screening for AIDs, discourage smoking, and so on.





- The body of knowledge and techniques used by public health workers -- the laboratories for making vaccines; the systems for collecting and analyzing data on rates of disease and death; the brochures that emphasize for school children the importance of washing their hands.
- The government services that aim to give everyone access to basic medical care -- emergency rooms, nurses who make home visits, food supplements for low-income families with children, clinics offering prenatal care, and so on.
- A collective effort to identify and address the unacceptable realities that result in preventable and avoidable health and quality of life outcomes, and it is the composite of efforts and activities that are carried out by people and organizations committed to these ends.

Ethics and Public Health: Important Questions

The development of actions and interventions for a contaminated community can be dependent on a number of factors. To help healthcare providers focus on ethics and public health it might be important to ask questions such as:

- What kinds of diseases are present as a result of the contamination?
- What kinds of health risks do community members face?
- What kinds of treatments are available?
- How accessible are such treatments?
- When should research be conducted and by whom?
- What kinds of patients should be recruited when conducting research studies?
- If research is conducted by local healthcare providers, will patients be truly free to decline participation?
- What prevention strategies should be used?
- What protections need to be in place?
- Who should be involved in decision-making?
- How much information about research findings should be shared with the community?
- When and how should that information be shared?
- How should benefits from research be allocated to participants and community members?



Those are difficult questions. Communities are built by humans and as humans we look at problems from different angles of vision. Indeed, there can be as many different perceptions of “right conduct” or “right approach” as there are residents! Unfortunately, people who hold one perspective do not necessarily agree with those who have a different view. And so, regardless of whether the environmental problems are caused by asbestos, by emissions from oil refineries, or by pesticides from farming, our ethical values and beliefs can compete with one another and disagreements can arise.

“They are very physical people, their work has been physical, and their recreation is physical.”

“Fewer people seem to talk to me about the mental health issues.”

Ethical Decision-making

Because an environmentally contaminated community has a “full plate,” it can be tempting to overlook or minimize the problems that do not pose an emergency. Richard Chambliss, a scholar who has written about healthcare ethics, says that his worry is not that healthcare providers will make the wrong ethical decision, but that they may not realize they are making an ethical decision at all.

Organizational constraints can also hinder recognition of ethical problems. Organizational theorists talk about concepts such as intra-organizational complicity and bounded rationality that condition staff to recognize some issues and not others. Other constraints such as limited or unclear protocols and conflicting agendas can also discourage recognition of and response to ethical issues.

Our studies indicate that healthcare providers may be hesitant to recognize or report ethical problems unless they think there will be:

- Shared recognition that an ethical problem exists;
- Ability to handle the consequences; and
- Belief that change or some solution is possible.

Given how hard it may be to take corrective action, healthcare providers need opportunities to talk about ethical issues with one another. These conversations should be interdisciplinary and should address the responsibilities not only of the individual but of the system. Participants in one of our studies reported that they learned that they were “not alone” in encountering problems. They characterized this insight as a major benefit.

“We need to get people together to talk about what our town will look like ten years from now when the EPA cleanup is finished.”

Healthcare providers can work together to develop some guiding principles to help them make informed decision when balancing the competing needs of the individual and the community. Examples include:

- Key principles such as respect for a person, truth telling, fairness and confidentiality should not be compromised;
- Systems should be patient responsive;
- Every effort should be made to provide adequate and compassionate care;
- The perspectives of patients need to be given fair consideration;
- Healthcare providers must strive to be honest about their role, scope of work, and abilities;
- Healthcare providers should make every effort to provide humane treatment based on scientific merit;
- Seek cost-effective strategies for prevention.

Even if we can collectively embrace these principles, there may still be fundamental disagreements about goals, processes, and outcomes. Some may emphasize the adherence to absolute rules and duties; others may emphasize the need to find the greatest good for the greatest number. Different perspectives and orientations should be expected. The challenge is to maintain dialogue and reflection so that various perspectives and belief systems can be acknowledged.

The Following Section Includes Helpful Ethics Resources

- Ethical Decision Making Chart
- Scale for Critical Thinking
- Roadblocks for Critical Thinking
- Scenarios of Ethical Dilemmas for Discussion
- Readers Theater Scripts
 - Tips for Developing a Readers Theater Script
 - Tips for Presentation of a Readers Theater

Ethical Decision Making Process

Determine the Organizational Foundation for Ethical Decisions

Golden Rule	ideal, includes avoiding harm and seeking good
Silver Rule	avoiding harm, a minimum requirement for ethical conduct
Tin Rule	acknowledging the potential for harm, but seeking the lesser of two harms

Clarify the Organizational Standard

Golden Rule	the best healthcare for the greatest numbers of people
Silver Rule	doing more than avoiding harm but not fully committed to the best healthcare for the greatest number of people
Tin Rule	pursuit of good without violating the rights of stakeholders.

Initiate a Process for Making Ethical Decisions

- Clarify harms to affected parties and seek the lesser harm;
- Weigh the potential harms, the consequences in terms of seriousness and quantity;
- Clarify the commonly accepted rules and norms for the culture/community this includes consideration of organizational, professional and cultural norms;
- Determine mitigating circumstances, chiefly, the capacity to act with knowledge and freedom;
- Develop strategies to minimize harm to those who may be harmed.

Develop Criteria for Outcome

- Seek the best that can be done;
- Clarify the minimal criteria for organization ethics standard you won't go below;
- Disseminate the accepted rules;
- Act with consistency;
- Seek ways to compensate the vulnerable and disadvantaged.

Asking Questions:

How do I know?
How is this situation similar and different from the previous ones?
Where did I get my information?
What standards am I using to assess my judgments?
How will I know my judgments are accurate?

Reflecting:

Take time to stop and think about what is going on;
Evaluate your state of mind;
Be prepared to explain your reasoning;
Think ahead to the next step.

Check Your Attitude And Willingness To:

Respect intuition as well as traditional thought;
Contemplate more than one approach and weigh the impact of each;
Consider other points of view, even when disagreeing;
Change opinion in the light of new evidence;
Take a position and defend it.

This scale was created by the National Rural Bioethics Project to serve as a guide when confronted with decision-making. Leaders can use this guide when conducting meetings to facilitate problem solving.

THEORETICAL FOUNDATIONS FOR DECISIONMAKING*						
Ethical Theory	Moral Rules Deontology	Virtues	Outcomes Utility	Principles	Care	Precautionary Principle
Basis	Duty/Rights	Virtues	Utilitarian	Principle-based	Care-based	Risk
Focus	Act	Agent	Consequence	Case-based	Power	Safety
Description	Actions are right or wrong – there are absolute standards. Focus is on fulfillment of duties.	Development of qualities, character, & integrity. Right actions are what a virtuous person would do	Weigh consequences. Choose actions that produce the greatest good; outcome matters	Four principles are standards for decisions;	Relationships, responsibilities, & power influence context & structure	Proof of safety to health & technology; avoid irreparable harm; concept of reasonableness
Approach	The ends do not justify the means; universal laws should be applied unconditionally.	Develop moral virtues in self & community – honesty, courage, integrity, truth, wisdom. Focus on motive & character	Considers impartial assessment of all interests; has beneficence as a goal. The ends do justify the means	Balance & apply the principles; May take specific circumstances into account	Value relationships, consider what influences action; attend to vulnerable populations. Commitment to others versus individual autonomy.	Guide to actions under conditions of uncertainty; identifies conditions when one should take reasonable measures
Benefits	Consistent rules & duties;	Cultivation of human excellence; considers act, motive, & character	Attention to consequences; considers interest of all	Useful, specific action guides. Autonomy is dominant principle	Looks at context & relationships; balances principle approaches	Reasonable response to credible threats; useful strategy when evidence is lacking
Challenges	Obligations can conflict when trying to apply rules in real life setting. There is too much emphasis on law and not enough on relationships. Abstract	Lack of agreement about virtues; a good character can do wrong & a bad character can do good	Majority can override minority. Can not predict outcomes; minority may suffer. Hard to determine what counts as benefits. Difficult to translate into practice.	Principles can conflict and can be hard to apply. Focus on individual autonomy may conflict with cultural values.	Power structures not always evident; lacks rules for consistent application; caring may impair objectivity so that important principles may be neglected.	Unclear what kind of proof is needed and how that proof differs from what is otherwise used or compulsory.

* Reflects ideas from Roberts, L. & Dyer, A. (2004). *Concise guide to ethics in mental health care*. Washington, DC. American Psychiatric Publishing, Inc.

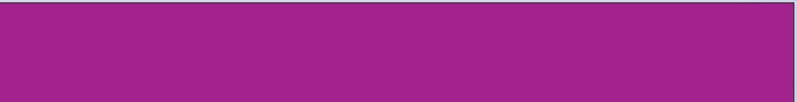


Roadblocks to critical thinking:

When two things appear related,
we often assume one causes the other;

We judge an outcome as likely if it is
representative of the population under
consideration;

We estimate the outcome of a situation based on
how readily we can think of examples of that
situation.



Scenarios for Discussion

Use The Decision-making Resources To Help Envision Solutions

Mrs. Smith has lived in Libby all her life. Her husband, a former plant worker, has been diagnosed with ARD. Their 17-year old son had seen the criteria for screening for ARD and wonders if he should be screened when he turns 18. Mrs. Smith asks you what they should do.

You have been asked to enroll patients in a research study that focuses on genetics and the potential susceptibility to ARD. You have approached a number of your patients and suspect that people enroll because they know you and receive treatment from you. How can you ensure that adequate protections are in place?

At the post office you are approached by your car mechanic who says he cannot afford to go to the clinic, but needs medications for sleeping problems and depression. He asks if you can help. What should you do?

Mrs. Berg calls you to let you know that her husband has made an appointment to discuss the results from his screening. She asks that you not tell him if the results indicate ARD, because he has stated that he will commit suicide if diagnosed. What will you do?

A 60-year old man with Mesothelioma has refused further treatment because “nothing can be fixed.” His children call you and demand that he receive treatment. What can you do?

A 25-year old woman reports that a large number of her family members have been diagnosed with ARD. She is worried about her genetic susceptibility to ARD. And wants your advice about whether she should have children. What can you tell her?

A community advocate has called you, a medical officer of the community health department, and asked for examination of cancer rates within the community. He made this request because he and other advocates believe that cancer rates are high. Your supervisor does not want you to respond to this request. What do you do?

A national respected research group has asked you to serve as a medical consultant for a study that the group wants to conduct in your community. The study will not provide any particular benefits to those who enroll in the study or to the community. What issues to you need to examine before making a decision about what to do?

A 65-year old man has been diagnosed with ARD. In spite of your warnings he continues to smoke heavily. He arrives at the ER with an MI, was placed on a respirator and has been on it for six days without any improvements in his health status. His wife wants you to keep him on the respirator. What should you do?

A 52-year old woman with advanced ARD has asked you to give her enough sleeping pills so that she can “put an end to things.” What should you do? What are the implications of your decision for the patient and for the community?

Readers Theater Scripts

Healthcare providers often have a leadership role in engaging the community in dialogue about sensitive issues.

Readers theater offers a way to engage a community in discussion about important issues. Readers theater scripts are based on stories and perceptions about community events and community problems. A readers theater script about Libby, for example, tells a story about asbestos contamination and the different perceptions, reactions, values, and expectations. Actual interviews and focus group discussions that took place in Libby comprise the lines of the script. This ensures that the script reflects local concerns and local language. The readings are fairly brief, about 20 minutes. The scripts are read by volunteer readers at community meetings. The process is informal and no training is required. Readers simply stand in front of the audience and read their lines.

There is, however, a twist. When conducting a readers theater presentation with a group of healthcare providers, for example, a nurse may be assigned the role of the administrator; the doctor that of the nurse, or even a patient. The administrator may play the role of a social worker, and a pharmacist that of the physician or a family member. When assigning roles for a reading in Libby a patient could read the lines of the EPA coordinator, an activist the lines of a business owner, and the EPA representative that of a real estate agent or patient. This role reversal among the readers gives an appreciation for what it's like to look at a problem from a different point of view.

At the close of the reading, the moderator directs a series of questions to both the readers and the audience. The questions highlight gaps and areas where there are vastly different perceptions between characters. They also help identify issues, options, learning points, and areas for improvement. Readers have repeatedly said that it was difficult to read another character's lines. "Oh it was hard, I didn't want to say those words," explained a nurse who was reading the part of an administrator. "But I could see that he had other responsibilities that were different from mine as a nurse."

Tips for developing a script:

For the opening, briefly describe the scene and circumstances where the conversation takes place;

Use active phrases and statements throughout the script, something that flows like a natural conversation;

Avoid monologues. Keep the dialogue succinct;

Focus on five to seven major characters;

Avoid any difficult or obscure language. Scripts need to be easy to read and easy to follow for both readers and audience;

Avoid using sexist, inflammatory or demeaning language;

Read the script out loud to test for ease and flow of reading. If you stumble over certain words or phrases, revise and use simpler language;

Underline or italicize words that should be emphasized.

Tips for the presentation:

Audience members find that name tags are helpful to identify the characters;

Readers should look up often from their scripts to engage the audience;

Highlight each characters' lines in their copy of the script.

**An example of a Readers Theater script is available at:
www.umt.edu/libbyhealth**

Chapter 6: Key Players: Engaging the Educational Community

“I hear about it when a student has a grandparent or an uncle or aunt who has it.”

Education helps us make sense of our lives. It opens new doors, helps us develop critical thinking skills, and offers directions and pathways for our lives. But education can also be unsettling. This is particularly evident in an environmentally contaminated community where education can make us more aware of problems like illness, shortened life spans, or community health risks.

An environmentally contaminated community requires initiatives that are tailored to address the diverse educational needs within a community. The educational need span the whole spectrum of community members including child through adult. Initiatives should serve K-12, alternative education settings, adult education and community colleges.

Some of these age cohorts can be served via the non-traditional efforts discussed in the chapter on building community collaborations. The school age population requires interventions that can be easily incorporated into the existing school curriculum. With that in mind, this chapter focuses mainly on strategies that support K-12 education, because our studies show that youth are often overlooked when designing programs or interventions for contaminated communities.



“Actually, the E:ABCs presentation about asbestos spurred conversations for about two weeks, with questions off and on.”

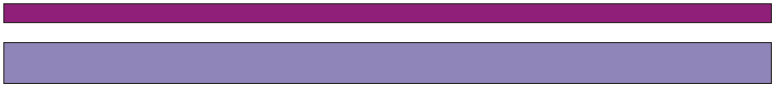
Getting Started

Most students are innately interested in bodily functions and how the body responds to both wellness and disease. In an environmentally contaminated community, students may have some familiarity with the consequences of environmental contamination and so may have many questions and concerns. In Libby, as in most environmentally contaminated communities, students experienced the loss of family members and friends; they faced fears associated with their own health screenings and potential treatments. Many questions arise. Will they eventually develop asbestos-related diseases? Will their lives be shortened? Some students struggled with their plans and expectations for the future. Is it reasonable to envision marriage or a career? Asbestosis can be a frightening diagnosis for young people. The absence of a cure can lead to feelings of depression, hopelessness, and a lack of direction.




Similar kinds of questions arise in any environmentally contaminated community and bring out the need to reflect on our basic beliefs about values, morals, duties and obligations. These questions help us recognize the need for well reasoned arguments that show respect and empathy for other perspectives. Students need to learn how to distinguish opinions based on emotions from those based on evidence. They need to find analytical ways to think about the issues they face as both individuals and community members. Ethics provides a way to work through some of the dilemmas students face when they live in contaminated communities. As they work through the dilemmas they may be able to seek workable solutions.

“Sometimes
students
have a
question
about it or
they just
want to tell
me about it.”



Although ethical dilemmas may loom large among the students, there are few venues whereby their fears and concerns can be addressed. The best place for discussing such issues might be among schoolmates and in the classroom. The teachers who might be the most logical leader of such discussions may, however, be hesitant to initiate discussions about ethics and the environmental contamination and its impact. The teachers in Libby, for example, told of their own lack of scientific knowledge about contamination and observed that class schedules and required curriculum created serious constraints with little room to address the asbestos concerns of their students. They also expressed their fear and hesitancy to talk about an issue that might be perceived as contentious in the community. It could potentially create divisions among the students whose families hold opposing views on the nature of the contamination.



“No, I don't think
people know about
predisposition.”

In addition, most teachers have had minimal training in handling psychological issues, such as depression and anxiety, which makes them hesitant to introduce such topics or act on them. In short, the community discord and the uncertainty associated with asbestos contamination made it difficult for the Libby teachers to address the issues of contamination in class. Rather than introduce topics for which they had little or no training, silence seemed the best approach.



“Mostly what I see is emotional; the kids are hurting because their family is hurting, and they don’t understand what is happening to them.”

But young people are the future of any community and it is important to incorporate strategies and approaches that help address the needs of this population. A good place to start is the school environment where teachers can be provided with useful and adequate resources. The materials and resources included in this chapter are designed to help educators find ways to bring sensitive topics associated with the environmental disaster to their students. That stated, we have not designed a formal ethics course for students. Rather, we are offering hands-on activities that allow teachers and students to experience how ethical conduct can lead to good decisions.

Objectives

The materials and ideas in this module are designed to assist educators as they:

- Help students recognize and discuss the range of issues associated with environmental contamination;
- Help students develop productive visions for the future;
- Develop and implement lesson plans;
- Help students recognize the ethical dilemmas associated with environmental contamination;
- Use projects and course work as a foundation for nurturing discussion.

“When the subject comes up about where the hot spots were, they think about the times their family was there.”



Anticipating Sensitive Issues

While it is important for teachers to actively address issues associated with contamination, it is also important to identify areas or issues that could prove sensitive. If done with sensitivity discussions among students can give a sense of community and help them sort out personal issues. Lesson plans should reflect strategies that take the following into consideration:

- When potentially sensitive issues are addressed (loss of a parent, discrimination, diseases such as asbestosis and cancer), special efforts should be taken to accommodate the needs of students who may find these discussions upsetting or embarrassing;
- Collaboratively develop norms and rules for class room discussion; these should be posted where they can be seen and revisited often;
- When differences of opinion arise, students should be encouraged to focus on the reasons justifying a position and not on personal arguments;
- Religious and cultural beliefs and other moral viewpoints are valid, but should be expressed in terms acceptable to everyone;
- Students should be encouraged to think about the impact their actions have on the environment, giving special consideration to future generations.

“It takes a while to understand what your doctor has explained to you, even when it's happening to your own body. ”

Classroom Activities

We have found that class room activities help students examine important ideas and their ethical implications. Classroom activities can help students discriminate between facts and values, duties and obligations. These core ethical concepts can serve as useful guides for classroom discussions and activities. The activities included in this chapter will help teachers address both content issues such as the science and process issues including how to discuss sensitive topics.

Sample Rules For Class Discussion

- Everyone has an equal voice
- Nobody gets to dominate the discussion
- Respect all viewpoints
- Don't interrupt each other
- Keep the focus on the ideas and facts not people
- Be patient

The material has been gathered from a number of sources and can be tailored to meet the needs of different age groups. Some will help address specific topics such as genetics and hazardous waste and some can be used for broader topics that will give students a chance to use their language skills as well as scientific knowledge. A number of these resources are available on the Libbyhealth website. There are also many federal websites that offer ideas and activities that can be incorporated into lesson plans.



Tox Town:

www.toxtown.nlm.nih.gov

Health Educators Tool Box:

www.metrokc.gov/health/educators/index.htm



Sample Introductory Activities

These activities are designed to introduce the topic of environmental contamination and give students opportunities to explore issues with one another. All or pieces of each activity can easily be incorporated into existing lesson plans or curricula.

Activity 1: Classroom Press Conference

The following activities are designed to develop skills in verifying facts, interviewing, note taking and writing while learning more about the historical, sociological and ethical implications of mining and processing hazardous materials.

Subjects: Language Arts, Current Events, Social Studies, Media Studies

Grades: 6-8, 9-12

Overview

Students arrange to have a guest attend their class, someone who can offer a good story for the school newspaper, if one exists. The class holds a press conference, interviewing the guest, then each student finds an angle and writes a feature story. The objective is for students to hone their skills in interviewing, note taking, and writing. The teacher might specify that the guest be from a certain segment of society or leave the decision totally up to the students.



Relevance to Environmental Contamination

Students in an environmentally contaminated community, such as Libby, have been repeatedly surveyed, interviewed and examined. The following exercise allows them the opportunity to become the surveyor, the interviewer, and the examiner. This activity offers a chance for some empowering role reversal that allows students to walk in the reporter's shoes and experience the difficulty of being the outsider who wants information. It also teaches the basic journalism skills of interviewing, note taking, and writing.

Suggested Time Allowance

One class period for preparation and one class period for press conference.

Objectives

Explore the role of the press conference in gathering news and the feature story in disseminating news.

Brainstorm as a group current issues within the community and people related to those issues who might make interesting guests for the press conference.

Invite guest for press conference and hold press conference.

Write and edit a feature news story based on information revealed at the press conference.



Resources/Materials

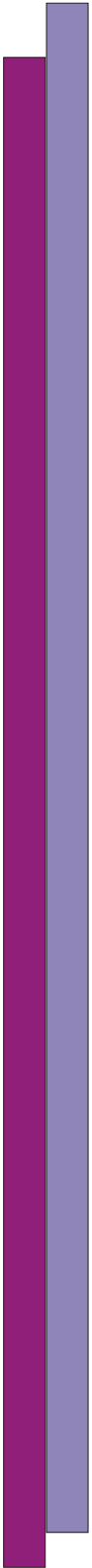
- One or two film clips of press conferences on different issues.
- Television with VCR
- Pens and pencils
- Paper copies of feature stories from the local or national media as examples. (optional)

Activities/Procedures

Record several two- or three-minute segments of press conferences, back to back. When students arrive to class on first day of the assignment, show the recording of the clips twice.

Ask students to respond to the following questions:

- What do all of the clips have in common?
- What defines a press conference?
- What are the important elements of a press conference?
- How should the reporter decide which questions to ask?
- How should questions be phrased in order to receive the best answers?



After a few minutes, ask students to share their responses and discuss the role of the press conference in gathering news.

- As a class, brainstorm a list of puzzling or troublesome situations taking place within your community and some people related to those issues who might be interesting guests. Once a list of choices has been generated, pick as a class the one person you would like to invite for the press conference.
- Decide on a student or a group of students who will be responsible for contacting the guest, making the official invitation, gathering background biographical information, presenting this to the class, greeting the guest on press conference day, and introducing the guest to the class. All students are required to take notes on this background info for use in their stories.
- Each student writes 10 non-biographical questions and submits them to the teacher for points in the assignment.
- Students meet the guest on press conference day, brings the guest to class, and introduces the guest to class.
- Guest is asked to make opening remarks. Then the class continues with the press conference, with each student using his/her list of 10 questions to interview the guest. Participation counts toward the final grade, so students are encouraged to ask questions.
- Students write a feature story, minimum of 300 words.
- Stories are graded and the best or several of the best stories are submitted to the newspaper, which chooses one for publication.
- Student who arranged the press conference writes a thank-you note to the guest.



Activity 2: Investigative Reporting: The Scavenger Hunt

Subjects: Language Arts, Current Events, Social Studies
Grades: 6-8, 9-12

Overview

This is a team activity in which students become investigative reporters in order to answer a list of 50 wide-ranging questions provided by the teacher. Some questions require students to go certain places in the community to find the answers; others require library research. The team with the most correct answers receives a prize. Teachers can customize the list of questions to direct students toward examining certain subjects.



Relevance To Environmental Contamination

One emphasis of the E:ABCs project is to empower people to make their own good healthcare decisions. This investigative reporting lesson teaches students the kinds of basic research skills needed to answer any kind of question, including health-related questions. If students learn a bit more about the resources around them, and the critical thinking skills required in solving research problems, they will have more skills to work with as they address the health problems in their community. They will also gain more confidence in their own ability to find answers to difficult questions, and even to devise difficult but important questions for others to answer.



Suggested Time Allowance

One class period in the library to get started; two or three days to complete the questions.

Objectives

Learn the importance of verifying information, including “facts” that are commonly accepted and answers from “experts.”

Develop basic research skills by using a variety of common resource materials and research methods to answer the questions.

Brainstorm with teammates and divide the work efficiently to meet the deadline.

Resources/Materials

Library reference department.

Computers for access to online resources.

List of questions compiled by teacher.



Types of questions might include:

- Questions that necessitate going into the local community.
- Who is the owner/operator of the local Conoco Station on Main Street? (There is a sign in the window with the owner's name.)
- Trick questions requiring students to confirm “obvious” information. Under the Articles of Confederation, who was the first U.S. president? (Although most people assume George Washington, it was John Hanson.)
- Questions that require very careful listening
- Questions related to the previous day's discussion in class.
- Questions that teach students about diversity.
- Which religion has the largest number of adherents in the world? (Answer is Islam.)



Activities/Procedures

Prior to class, create a list of 50 questions that require a range of resources and materials including online resources, phone books, almanacs, etc.

Students are placed in teams and told that they are going on a scavenger hunt. Give each student the list of questions and tell them that they require a range of activities from actually going someplace in the community, to visiting an online resource to using basic resources found in the library.

Students' work in teams, spending the remainder of the class period in the library where they can begin their research.

On the due date, students and teacher review questions and answers in class. The team with the most correct answers wins a prize.



Related Assignments

- Lesson can be completed in conjunction with Press Conference lesson, using the 50 questions as a way to explore issues in the community before deciding on a guest to invite to the press conference.
- Ask students at the end of the Scavenger Hunt to identify the question they enjoyed the most and write a brief essay on why.
- Ask each student to write five questions (with answers) that might be used in a future scavenger hunt and to explain what skills the questions would test.



Sample Mid-level Activities

Activity 1: The EPA

Subjects: Language Arts, Current Events, Social Studies, Media Studies

Grades: 6-8, 9-12

Overview

EPA has designed a series of innovative activities that teach concepts associated with environmental contamination. Some of those have been specifically designed to help students develop skills in critical thinking, problem solving, and decision making. One of the components, HAZ-ED, can be used as either part of a larger curriculum or as a special stand-alone activity.

Activities on the HAZ-ED website span a broad range of areas from warm-up activities to risk assessment. Sample topics include:

- Defining Hazardous Waste
- The Numbers Game
- Superfund Program
- Risk Concepts
- What Is An Aquifer
- Common Clean-up Efforts



Activity 2:

The National Human Genome Research Institute

The National Human Genome Research Institute has designed a number of genetic education modules for teachers. These include specific teaching plans to present the history, facts and genetic terminology behind the Human Genome Project, and the ethical, legal and social questions surrounding the discoveries and advancements of this research. This information is available at the following website: www.genome.gov/10005911 for additional information.

Sample topics include:

- How to Sequence a Genome. Students can learn how to organize concepts into an outline and then present the concepts verbally. The method for sequencing the human genome that is being used by the National Human Genome Research Institute can be easily understood and used as a model for student discussion. The science behind each concept is explained on the site using animations, an image gallery, video interviews, problems, biographies and links.
- Genetic Mind Reader. Genetic Mind Reader is a game that reviews some important concepts and terms relevant to the Human Genome Project and genetic research. The game is played like a mind reading session between two teams. The question is presented by a student saying: "I am thinking of a genetic concept..."



Sample Advanced Activities

These activities require more time and effort and may span an entire semester or even a year.

Activity 1: How We See It: Documentaries Through the Eyes of Children or Young Adults

Subjects: Language Arts, Current Events, Media Studies, Social Studies.

Grades: 6-8, 9-12

Overview

This lesson allows students to develop the skills practiced in previous lessons verifying facts, interviewing, note-taking, and writing while learning to put together a film. Students explore the power of documentaries to present realistic and sometimes difficult perspectives on events. Students choose current issues that interest them and create their own documentaries, presenting the issues through their own eyes or the eyes of other children. Ultimately, the class might produce a school-wide film festival and see their films aired on community television.



Relevance to Environmental Contamination

This lesson allows the same kind of empowering role reversal as the Classroom Press Conference lesson, but it goes a step further in that it offers students the opportunity to tell the story of their town as they see it. When the students in Libby tackled the asbestos contamination through a documentary film project, they gained the opportunity to tell about the contamination from their perspective. This allowed them to explore what they had been told by all the various experts, their parents, and their teachers.

This film project also offered an opportunity to link the youth of Libby to youth living in similarly affected communities across the country. The film project also provided additional benefits by giving the students an opportunity to lend peer support and share information.



Suggestions

- Explore examples of documentary films and discuss their format, point of view, and ability to convey messages.
- As a class, brainstorm current issues within the community.
- Divide into groups based on interests and discuss issues chosen to be the topic of a documentary.
- Shoot and edit documentary.
- Present documentary to class or at a film festival.

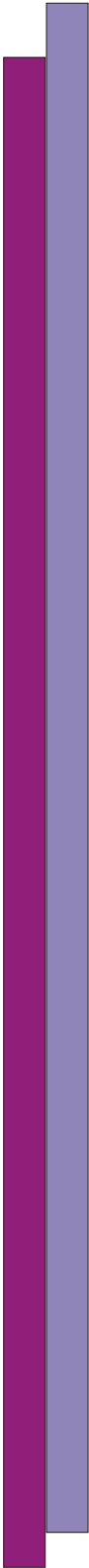
Resources/Materials

- Several 30-second film clips from television documentaries on different current events issues.
- Television with VCR.
- Video cameras (one per group)
- Pens, pencils, and paper.



Activities/Procedures

- Prior to class, record four or five short clips from documentaries on television about different current events issues. Show the recording to students twice when they arrive at class. Ask students to free write for several minutes on the following questions:
 - What does “documentary” mean?
 - Whose point of view is the story told through in each of the clips?
 - How does the point of view impact the story?
- As a class, brainstorm a list of interesting or troublesome issues in your community. After the list is generated, students divide into groups based on the topics that interest them. Each group should have between three and six members. Discuss the chosen topic in your group, focusing on the following questions, which should be written on the board for convenience:
 - Why does this topic interest us?
 - What do we already know about this topic?
 - What questions do we still want to ask about this topic?
 - Where can we find the answers to these questions?
 - As adolescents, what is unique about our point of view on this topic?

- 
- After 10 to 15 minutes, the group should begin to brainstorm a documentary on their topic as seen through their own eyes. Groups should use the following questions as guidelines in developing the film:
 - Which people involved in this situation might help shed some light on the topic?
 - Which locations do we want to focus on in then film? Take practical considerations about time and cost restraints, safety, and privacy issues into account.
 - Who should be the star of the film? Can be a student in the group or some other young adult.
 - What techniques will we use to capture both the reality of the situation and the way it is perceived by a young adult?
 - In a future class, the group creates a story board, laying out each scene. Then, each group should shoot the footage for their film.
 - Finally, groups present their films at a classroom or school-wide film festival. They might even speak with the community television station about airing the films on TV.



Closing Thoughts

Students need opportunities to identify the problems they face, identify the different perspectives, and determine a reasonable course of action. Our experiences in Libby have shown that when activities are offered to students the whole community can benefit. The students who participated in a documentary film project learned skills and ways to approach problems that will have long term implications. Several of the students said that the experience with the documentary gave them confidence to think about college, a relatively non-traditional choice in this community. One student decided to start a small business to offer video filming of community events, including weddings and family reunions. The students showed a portion of their film at a community health fair where they received accolades from the seniors in the audience. We have learned that the potential benefits for any of the suggested activities extend well beyond the class room.

Notes

Chapter 7: Stepping Up to the Plate: Protecting the Health of the Community

“And I only want to live long enough to have an EPA sticker of approval on both ends of town.”

When an environmental disaster strikes, many agencies, groups, and individuals become part of a community response. Some of these entities may never have had any reason to participate in a public health effort. They may never have had to seriously examine the ethical values that shape public health decisions. But suddenly community members become part of a collective effort to assure the health of the community and so have to assume new leadership roles.

The new leaders will have to evaluate community understanding of the issues, identify all of the various community members who need to be involved in decision-making processes, and determine how the issues and the people can be brought together.

Key tasks include:

- Raising awareness
- Increasing collaboration
- Developing and sustaining community leadership
- Facilitating change
- Maximizing opportunities for healing

Key Players: Community Leaders

The amount of knowledge needed to undertake the new role may seem overwhelming. Community leaders have to examine what happened and what that means for the community. They have to familiarize themselves with basic concepts of ethical conduct including:

Informed Consent which is a process that has three key elements involving the purpose, procedures, risks, benefits and alternatives of the study:

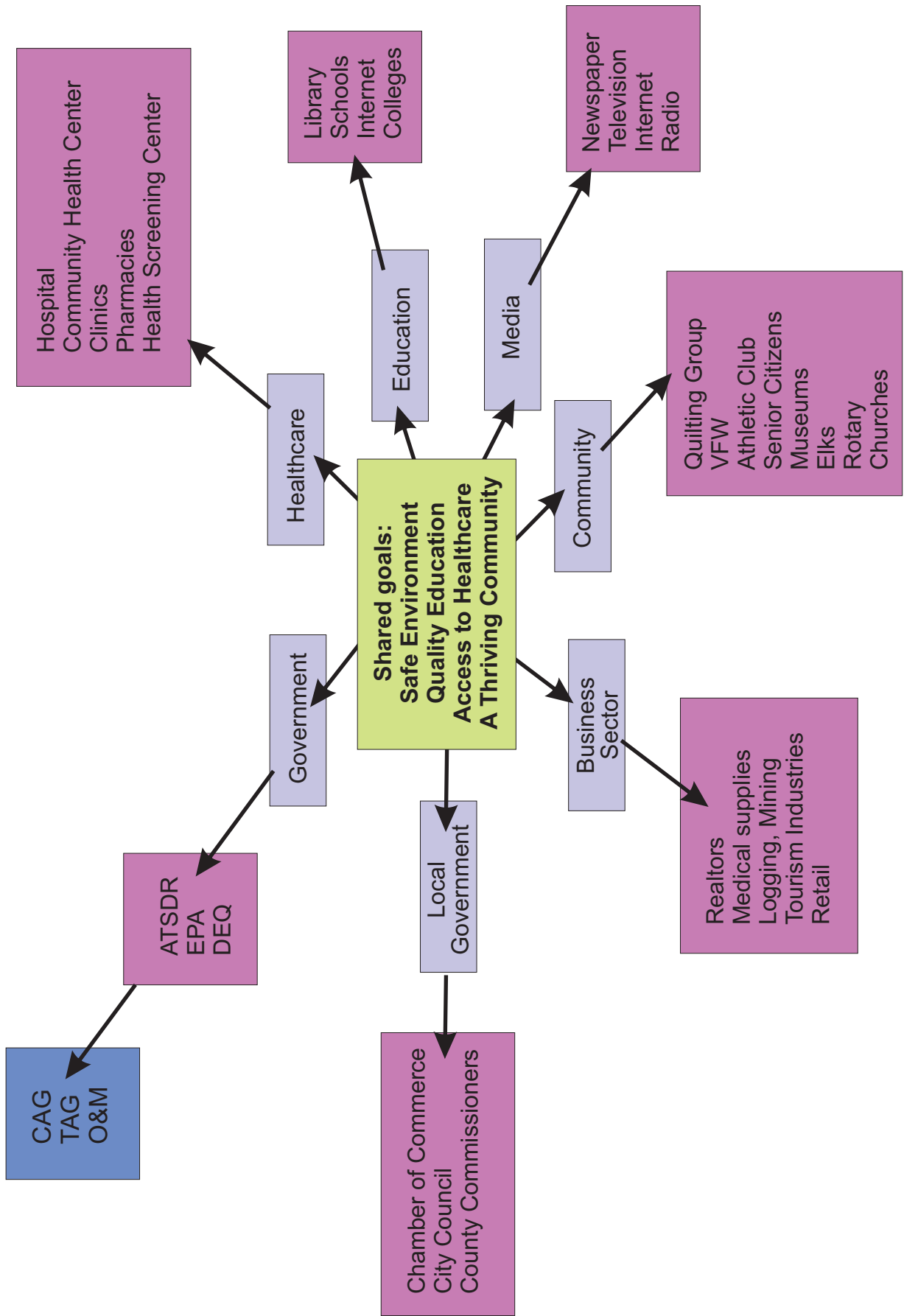
- Provision of information;
- Comprehension of information, and;
- Voluntariness.

Consent to participate in research or treatment is *only* voluntary when there is a reasonable option for the participant or patient to withhold consent. The implicit or explicit power of investigators or their institutions can reduce the voluntary nature of participation.

Autonomy and Decisional Authority involves expectations about decisionmaking processes. The US emphasizes personal autonomy but “respect for persons” and decisional authority may also be defined by tribes, religious leaders, community leaders or other special cohorts.

Standard of Care or equipoise refers to the general acceptance among scientists and healthcare providers that patients or prospective research participants should not be subjected to greater risk through research than they would be if they were receiving standard therapy. Standard of care involves two broad categories: the best treatment possible without respect to location and the best treatment possible within a given context or locality.

“We all need to get on board together to support getting the science done.”



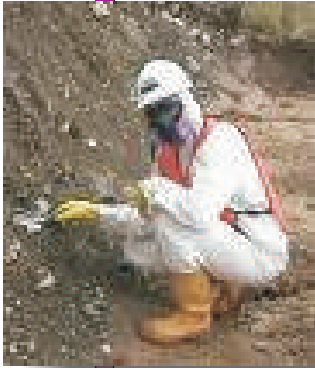


“People are aware that certain families get hit more than others.”

Risk Assessment involves hazard identification, exposure assessment, toxicity assessment, risk characterization, and uncertainty analysis. Each one of these components presents its own challenges. It is not always possible, for example, to measure direct exposure, concentrations, or levels at which health effects occur. Results need to be weighed against confidence in the data, community concerns, state regulatory concerns, remediation costs, effectiveness and permanence of the remedy and other factors.

The key players within the community must also gain competency in key concepts of ethical research including:

- **Scientific or Social Value of the Study:** analysis of the value of the study to ensure that it will improve the health and wellbeing of the individuals and communities involved.
- **Scientific Validity:** application of acceptable scientific principles and methodologies, including statistical techniques, in order to produce valid data.
- **Fair Subject Selection:** vulnerable populations will not be exposed to risky research, and rich and powerful individuals will not be selectively chosen for potentially beneficial research.
- **Favorable Risk-Benefit Ratio:** efforts must be undertaken to minimize risk and enhance benefits. Risks must be proportionate to the benefits that will be derived.



- **Independent Review:** there must be ethical review of the study design, potential research participants, and the risk-benefit ratio by a group unaffiliated with the study. This is often provided by entities called Institutional Review Boards (IRB).
- **Respect for Subjects:** respect involves permitting people to withdraw, protecting privacy and confidentiality, providing information about risks and benefits, providing feedback about results, and maintaining the wellbeing of participants.

“Some people are scared to move here.”





Obtaining Information

Multi-method data gathering approaches such as surveys, interviews and focus groups help identify community strengths and deficits when facing an environmental trauma. They help us consider key characteristics and features of the community, identify community interests and concerns.

Questions for consideration include:

- Who speaks to whom?
- Who is trusted?
- Who are the leaders?
- Who dispenses information?
- What are all the different agencies and perspectives that need to be considered?
- How and when will data be shared?
- How are efforts coordinated?

Translating/Sharing the Data

Once the information has been gathered and analyzed it is important to share it, in a timely fashion, with people who need it. In Libby, for example, we found it important to:

- In addition to holding on-going meetings as needed, arrange special meetings for persons who are disadvantaged, vulnerable, or hard-to-reach for other reasons. This commitment to sharing information is particularly important at the beginning of the process because it builds trust and encourages active participation of community members when decisions are being made.
- See information sharing as a long-term commitment. Don't expect instant acceptance or instant agreement. Be patient and respect each organization's decision making process. People, even when they are the key decision-makers, are not always all on the same page at the same time.
- Use the communications networks that are already in place and trusted. Community health clinics, senior centers, schools, and VFW programs are excellent ways to reach disadvantaged and other hard-to-reach groups in many communities. Churches can also be very effective in reaching diverse groups in the community.
- The messenger can be as important as the message. Individuals are more likely to listen to people and groups they already know and trust. A flyer received from a trusted community organization has instant credibility; the same flyer sent through the mail or received from a stranger may not. Identify community messengers who are trusted, who can help explain the issues and help shape the message in ways that it will be understood.

“The locals are proud and want to handle things themselves.”

“Some think that only the people who smoke cigarettes will get it.”

What We Learned In Libby

Even in a relatively small community, such as Libby, it can be very difficult to achieve a coordinated approach. Many of the agencies, groups, and individuals had specific and different agendas. At times these agendas conflicted with one another. An individual's authority in one area of community affairs may not translate into authority in another. An acknowledged community leader may not provide the desired access to a group's evolving needs and views.

It can be tempting to choose, as leaders, the most visible community members for multiple projects. But the repeated participation of a select few may exacerbate existing power differentials within a community and create “career activists” who are increasingly estranged from and resented by the group they are intended to represent. Finally, factors such as socialization, professional training, and work experience may distance professional members of a targeted community from the group's mainstream and even more vulnerable members.



Key Players: Government Agencies

ATSDR, EPA, and the DEQ were some of the first agencies to descend on Libby after the story broke. These agencies were viewed with suspicion and the relationship with the town was strained and contentious. Community members learned that it simply takes time to develop and nurture trust with the government agency representatives.

Federal Government

Agency for Toxic Substance and Disease Registry

(ATSDR) set up free public screenings for asbestos related disease (ARD). The agency has compiled the results from the screening and have published several mortality studies based on that information.



The Environmental Protection Agency (EPA) offers a number of services to ensure community participation in decision making. These include:

- **Community Action Group (CAG)** consists of leaders from the hospital and clinics, school, churches, city council, newspaper, former WR Grace employees and other community members with a strong desire to stay informed and participate in discussions and decisions regarding the health and proposed clean up in Libby. This group hired a facilitator and holds monthly meetings. Minutes from these meetings are posted on the E-ABCs website.
- **Technical Assistance Group (TAG)** functionaries include a hired Technical Advisor and a group of volunteer board members. The technical advisor is an expert who reviews documents prepared by EPA and advises the TAG board. The TAG, in turn, can then inform the community about the ongoing cleanup process. They also give EPA input and feedback on clean-up design plans.
- **Operations and Maintenance Group (O&M)** are created to ensure that the community participates in decisions about their town. When EPA leaves the O&M becomes active in on-going clean-up efforts.

State Government

Department of Environmental Quality (DEQ) is a state department in Montana charged with the asbestos cleanup in Troy. The DEQ is also providing outreach services such as articles in the local paper that provide information on the cleanup process and access to an 800 number for the EPA Info Center in Libby.

Montana Asbestos Screening and Surveillance Activity (MASSA) is funded by ATSDR, and coordinated by the State Department of Health. MASSA performs free screening for asbestos related disease to people who meet the criteria for exposure.



“If the EPA says the lumber mill has to clean up the asbestos at their mill, they'll go bankrupt and they'll close it.”

Local Government

County Commissioners
City Council
Mayor

The local government become involved in a wide array of policy decisions related to health, welfare, community sustainability, and abatement efforts. For example, in an effort to reduce the air pollution, the health department in Libby launched a woodstove exchange program whereby old and inefficient woodstoves were replaced with more efficient ones.



“The VFW has blamed the asbestos situation for their financial problems.”

Key Players: Healthcare Community

Local Hospital
Community Health Clinics
Specialty Clinics
Pharmacies

The healthcare community found themselves facing a broad array of new and unfamiliar health problems caused by the contamination.

Center for Asbestos Related Disease (CARD) is an independent clinic that provides pulmonary care for ARD patients.

CARD Outreach for Recovery Assistance (CORA) was initially funded through a grant from Substance Abuse and Mental Health Services (SAMHSA) to provide psycho-social support to local residents. St. John's Lutheran Hospital added in-kind support for the program, and fiscal support came through a contract with The Center for Mental Health Services, Emergency Mental Health and Traumatic Stress Services Branch.

St. John's Lutheran Hospital (SJLH) set up a specialty health care facility specifically treating those exposed to asbestos. They worked with ATSDR to screen some 7000 former and current community members.

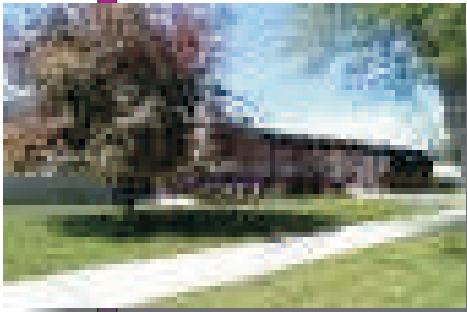
Community Health Center (CHC) was funded through a grant from Health and Human Services (HHS) to provide health care to the uninsured on a sliding scale.

“We need to get the asbestos cleaned up in town and have the government say, “Yes, you have a certified stamp on Libby. It's clean.”



Libby Asbestos Medical Plan (LAMP) provides supplemental benefits related to asbestos exposure including screening and treatment as the payer of last resort. Money to fund LAMP resulted from a lawsuit of EPA vs. Grace.

Health Network of America (HNA) is the medical program funded by W.R. Grace. It provides ARD medical and prescription coverage for people who are accepted into the plan. The plan is administered through a third party and does not operate under insurance company industry standards.



Key Players: The Schools, The Media & Other Community Organizations

School District
Community College
Public Library

The educational community became important sources of information. Changes in the K-12 school curriculum were made to address asbestos contamination. New courses were added to the community college curriculum. The public library created new sections, bought new books, and increased Internet access.

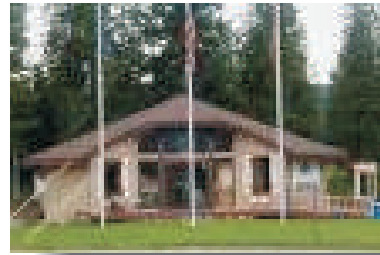
Media

Newspaper
Television
Internet
Radio

The media became a vital source of information on the environmental disaster. Given the broad and competing perspectives in the community, impartiality and accuracy in reporting were and are major concerns.

Community Groups

VFW
Athletic Club
Senior Centers
Rotary
Elks
Quilting Groups



Local established groups in the community get involved in different ways. The Quilting group in Libby created a quilt to express the impact of the environmental damage. It is displayed at a health clinic in Libby. The Athletic club began to offer pulmonary exercise classes and nutrition information.

Business Sector

Chamber of Commerce
Local Businesses
Retail, Logging, Mining, Realtors, Tourism Industry

Those in the business sector have very different needs and agendas for what they think is best for their community. In Libby some businesses, such as medical suppliers, saw an increase in profits; other businesses experienced lost profits due to the stigma of being declared a Superfund Site.



Communication: An Essential Ingredient

As these groups represent people have different beliefs and norms, organizations, and power structures a good communication approach becomes essential.

- A communication strategy is not a definitive plan; make it thorough, but not too elaborate and then move on to the next task;
- Communicate in a way that is flexible enough to allow for new information;
- Review outreach strategies often to remember the goals, purpose, and audience;
- Communicate the most essential information;
- Document successes and shortcomings to learn how the outreach strategy might be improved;
- Work closely with the local media to publicize information. (The local media can be particularly helpful during milestone events in the Superfund process).

Success Stories

In Libby we have found that using work groups with *specific* goals have been quite successful. They seem to work better than strategies like support groups that offer help and sympathy. While more than one resident has said, “I don't need my hand held” a working group with a common goal provided an opportunity to share experiences in a socially acceptable manner.

Successful projects include:

- **ARD-Net** was created to bring health services providers to the table. Different sectors such as educators, or business owners could also use this network approach for their constituencies.
- **Asbestos Health Fair** is an annual community wide health fair was created by healthcare providers and businesses to convey information about products and services. One central location proved a good way to provide information about financial resources for ARD healthcare, home assistance, and healthy behaviors. The fair also provided an opportunity to test equipment, learn breathing exercises and get advice on smoking cessation. The fair also provided a forum for scientists who presented the results from their research. The fair in Libby has also become a social event and a chance for neighbors to have a cup of coffee together, share their experiences, and chat.



- **Computer Donations** by the The University of Montana were coordinated by the E-ABCs project. U of M donated twelve used computers to various non-profit agencies in Libby. These agencies included the Lincoln County Library, the Libby Schools, the Heritage Museum, the Senior Center, and the Victims Hotline.
- **Asbestos Symposium** illustrated connections between Libby and asbestos controversies occurring nationally and internationally. It included seminars, lectures, a film series, a photo exhibits, and other activities for the general public.
- **Community Asbestos Memorial Project (CAMP)** was formed several years ago by volunteers who wanted to work with the city to create a permanent memorial. They wanted the memorial to serve as a visible symbol of what had taken place in Libby. The group appeared before the city council and the county commissioners to secure a permanent place for the memorial. The City of Libby and the CAMP group has decided on a beautiful location at a park on the river. The location is particularly appropriate because it was a primary cleanup area when EPA first came to Libby. The memorial project gave its members a project to focus on while working through their grief.



- **An Ethics and Research column in the local newspaper** provides articles on research related to asbestos is coordinated through Ethics: A Bridge for Communities and Scientists. The E:ABCs project is charged with translating and disseminating scientific information so residents can make informed decisions about their health and well-being.
- **The Heritage Museum Project** began when the E:ABCs on-site project manager, the Heritage Museum Board of Directors in Libby, and the Missoula Art Museum started working together to create a permanent educational exhibit about Libby asbestos at the Heritage Museum.
- **The Libby Quilt Guild** created a beautiful quilt in which each square was quilted by a member of the guild whose life had in some way been touched by the asbestos disaster in Libby. The finished product was displayed at the Missoula Art Museum as part of an asbestos exhibit and is now on permanent display at an asbestos healthcare clinic in Libby.



Chapter 8: Moving On

Introduction

We began this manual with a discussion of the uncertainty and distress that accompany environmental contamination. Throughout, we tried to demonstrate how ethically informed approaches can help communities find workable and practical solutions for the problems they face. During the course of the five-year E-ABCs project we learned again and again, there are no quick or easy solutions when dealing with environmental contamination. While progress has been made in Libby, the uncertainty and distress continue. Much is yet to be learned about risk factors and the health effects of the contamination, the feasibility of remediation, and the economic prospects for recovery.

A community is not a static environment and as the months and years pass, issues change, leadership changes, and the urgency with which the community initially approached the contamination diminishes or changes in direction. The desire to move toward recovery can mitigate important lessons from the past. In Libby, the need for stable and reliable jobs initially made the vermiculite mine seem central to the overall well-being of the community. The closure of the vermiculite mine was economically devastating for many families. Losses were exacerbated when, in more recent years, a lumber mill that provided employment for many families also closed. This community was very dependent on these businesses as key employers and as community benefactors.

“We need
to look for
more
expansive
yard
cleanups.”
EPA
Representative

The community wants to recover from these losses and build a new and vigorous economic base. The community's need to replace these sources of employment creates certain vulnerabilities. In recent years EPA cleanup activities have become a major source of employment.

Efforts are underway to open a silver mine with hopes that a different kind of mine will not pose health risks. While that may be possible, without careful deliberation the community may yet again make decisions that enhance the local economy but compromise the health of community members.

Our experiences in Libby show that communities need to create many opportunities for people to discuss and explore their expectations, hopes, and values. These opportunities need to address the expectations and perspective of all stakeholders, from school-aged children to members of the business community, to the senior citizens. When framing community wide discussion, we stress the importance of exploring “who does what to whom and how, and under what circumstances, and to what effect?” We always try to bring as many people and as many segments of the community to the table as possible. When people work together the results can be tangible.

“Laborers who spend their days working in Libby dirt – from the workers of the major restoration firms earning EPA coin to smaller private contractors – face risk factors largely unchanged since the story blew up in 1999.” Engineer

Sustaining the Efforts

During its five year funding cycle, the E-ABCs project has looked for approaches that help a community obtain scientific information and make ethically sensitive long term decisions that honor the inter-related economic, social, political, and cultural factors that impact both actions and decisions on a community level. Many of the activities were possible because the project hired a full-time local outreach coordinator. For most of the efforts described in this manual, the coordinator provided important leadership and served as a liaison between the researchers and the community.

The coordinator supported health efforts through her help participation in the community-wide ARD Network and as organizer for the annual health fair and vaccine campaigns.

She helped to develop newsletters for patients and posters and handouts for waiting rooms in various clinics. She supported business efforts by becoming a member of the local business networks. She became a resource in the education system providing talks in various classes, and helped in coordinating the student film project.

In addition, the coordinator supported community-wide initiatives through her service on the EPA TAG Board, attendance at CAG meetings, participation and projects at the local museum and memorial garden. She coordinated the donation of computers to various agencies throughout the community and provided training when needed. In addition she participated in letter writing campaigns, grant writing and many discussions regarding additional in-home non-medical help for patients - including development of a position of a volunteer coordinator in the community for this type of assistance.



The importance of the coordinator's contributions can not be overstated. She was able to bridge the interests of diverse agencies and find common ground. She became trusted as a fair and impartial resource who was truly invested in the good of the community. This was possible because there was financial support for her full time employment.

As the E-ABCs Project comes to an end, the community faces challenges in determining how progress can be sustained. Many of the efforts that were initiated or supported by the E-ABCs project will continue beyond the duration of this effort. Many school based activities, including the film project have been incorporated into the school curriculum. The memorial garden and the new exhibits at the museum will be sustained through community volunteer efforts as well as commitment from the city. Local businesses will continue the business the work of the Job Service Economic Council. The local hospital, clinics, and health other health-based agencies will continue the health fair.

Other efforts may be more difficult to sustain unless the community finds the resources to support an outreach coordinator who can successfully serve as a coordinator and liaison among all different community entities. For example, the coordinator provided considerable administrative support to the EPA TAG board. She served as a board member, helped develop their website, developed community surveys and mailing lists. These services will now have to be assumed by others who may not have the time to devote to such an effort.

Moving On and the Precautionary Principle

One of the most serious issues for this community is building a viable and sustainable economy. As noted previously the community is currently assessing the viability of a silver mine to replace the jobs lost in the timber industry as well as from the closure of the vermiculite mine. Many residents are cautioning that the old lessons may be forgotten and that decisions will be made based on the prospects of short term gains and profits. As the community struggles with these decisions, all points of view need to be considered before decisions are made.

Some communities across the country that face similar issues, have found that the Precautionary Principle offers a workable and practical approach for long term decision-making. This approach is structured to address situations in which there is uncertainty and absence of a scientific consensus about potential harm. It states that if an action such as opening a new mine might cause severe or irreversible harm to the public, the burden of proof falls on those who would advocate taking the action.

“The airborne asbestos exposure during routine work tasks [at the country club golf course] is 100 times greater than that of most Libby residents.”

EPA Representative

The precautionary principle is often applied when assessing the impact of human actions on the environment and human health. The impact on both the environment and health involves complex systems where the consequences of actions may be unpredictable. When applied to environmental policy, the precautionary principle stipulates that for practices such as the release of radiation or toxins, massive deforestation or overpopulation, the burden of proof lies with the proponents.

In economics, the precautionary principle has been analyzed in terms of the effect on rational decision-making of the interaction of irreversibility and uncertainty. If outcomes of decisions are irreversible, they need to be weighed against decisions that allow for more flexibility in the future.

The precautionary principle is particularly useful in environmentally contaminated communities because it offers a way to look backward as well as forward. In a community like Libby, for example, there is great deal of uncertainty and irreversibility with respect to health risks, environmental policies, and economic strategies.

“We [EPA] provided the data to the golf course and they are taking steps to mitigate. But we aren’t telling people you can’t live in their yards either.”

EPA Representative

We present the following example to show the value of applying the Precautionary Principle. In Libby, many households rely on wood burning fuel for home heating. Because the community experiences frequent inversions, this practice further compromises the air quality in the valley. To remediate this problem, the County Health Department coordinated an effort to replace old and inefficient wood stoves with new and more efficient ones.

In the midst of the stove exchange program researchers found that large amounts of asbestos fibers were lodged in the bark of trees in areas across the county. Thus a number of new issues needed consideration. Should the stove exchange program continue? Would asbestos fibers be released through wood burning and cleaning of stoves? Was it safe to burn wood gathered in the area? Where are there sources of non-contaminated wood?

As the town of Libby grapples with these kinds of issues, it might be helpful to apply some recommendations provided in the Precautionary Principle literature. As a starting point, the recommendations include a checklist that town members might use when trying to make well informed decisions.

This checklist is best applied early in the decision-making process, but can also be helpful for analyzing, clarifying, and challenging existing knowledge and approaches.



A Precautionary Checklist

1. **What do we care about?**
2. **What are we trying to accomplish?**
 - a. *Who shares this goal?*
 - b. *Do the goals reflect what we care about?*
3. **What choices do we have?**
 - a. *What is feasible and likely to move us toward the goal?*
 - b. *How do choices compare and rank?*
 - c. *How do we find even better solutions?*
 - d. *How do we adopt better solutions?*
4. **What is the bigger picture**
 - a. *What are the “upstream” problems” What the “downstream” repercussions”
What is the broader context?*
 - b. *What are the earlier solutions? The most elegant? Is there a systematic
solution that could create multiple benefits? Where can we intervene in the
system to set in motion the best solutions?*
5. **Do we know enough to act? Do we know so little we must act with caution?**
 - a. *How would we know if harm was occurring or about to occur?*
 - b. *What do we know about harmful effects?*
 - c. *Where does our knowledge come from?*
 - d. *How can we predict from what we know already?*
 - e. *Do we know enough to act?*
 - f. *Do we know so little we must act with caution?*
 - g. *Are we getting all the information we need from those who have it? Is testing
thorough? Is monitoring adequate? How will we learn?*
6. **Who is responsible?**
 - a. *Are those responsible accountable?*
 - b. *Is government acting responsibly as public trustee?*
 - c. *Who has the burden of proof those who might harm or those who might be
harmed?*
 - d. *How can we distribute power, costs, benefits, and responsibilities more justly?*

This checklist is from the book: Myers, NJ, Raffensperger (eds). *Precautionary Tools for Reshaping Environmental Policy*. Cambridge, MA: MIT Press, 2006.

Final Thoughts

The E-ABCs project showed that an ethically attuned community education initiative can help a community deal with the effects of an environmental contamination. The project's efforts to launch cooperative programs for school age children and senior citizens, exhibits at the local museum, a memorial garden, and ongoing articles for the local newspaper were applauded. Our experiences suggest that a community-focused education initiative can help a community engage in and sustain dialogue.

Our project also shed light on major challenges that influence long-term decision making in a contaminated community. The foundation for informed decision making requires access to and understanding of complex scientific concepts and knowledge. Access and understanding are sizable challenges as it can be very difficult for a community to deal with evolving and even competing scientific knowledge, as was the case with the asbestos contamination experienced by Libby. Without scientific certainty, there is more room for divisiveness and denial. And in Libby, scientific certainty about the impact of asbestos exposure remains in question. Not all of those who are exposed to asbestos become ill with asbestos-related diseases; the latency period for disease can be long. The extent to which other disease processes may be related to asbestosis is under question.

The uncertainty about the effects of exposure and the determination of risk were underscored when a publication entitled *Some Facts About Asbestos* (FS-012010) was recently removed from the list of available reports on the USGS website. Although the mineralogical data are still valid according to a USGS official, the fact sheet did not include information on the forms of asbestos, winchite and richterite, that are found in the Libby deposit. Moreover, new reports on the health effects of exposure to non-asbestiform amphiboles have been published since 2001 and this information should be included in an updated fact sheet. That same official, however, explained that there are no plans to update the fact sheet anytime “soon.” A publication written by the EPA called *Living With Vermiculite* was similarly removed and had to be rewritten. So the community is, in a sense, always dealing with a moving target and new or updated information can bring new fears.



A number of scholars have noted that this level of uncertainty can deepen divisiveness and denial in contaminated communities. It is easy for people who are not sick to deny the scope of the problem because the notion of being “sick” threatens their basic assumptions about how the world works. One's environment should not be a source of harm. Thus a toxic exposure disrupts the fundamental understanding about what to expect from the world around us. If the harm were so serious, would not the government have intervened and protected the citizens?

Divisiveness and denial can also arise because researchers have found that while members of the public tend to see natural hazards as acts of God whose effects can only be mitigated, technological hazards, like the asbestos contamination in Libby, are assumed to be amenable to “fixes” of various kinds and so amenable to substantial reduction. The community of Libby embraced the concept of “fixing the asbestos problem” so Libby would be a safe place in which to live. Efforts to identify pathways of exposure and programs like the health screenings were



applauded because people saw them as steps on the road to a final fix. In a sense, the community residents' tolerance for risk was quite high as long as the EPA cleanup efforts were progressing. There was a light at the end of the tunnel: the community could be clean and safe. This was an enticing vision, especially for a community that is marked by great natural beauty, multi-generational ties, and socio-economic features that make the prospects of moving, obtaining new employment, and buying a new home seem impossible. Thus rather than believing that one should possibly move from the community, residents lobbied for extensive clean-up and investment in new businesses including an international research center with visiting scholars.

This tenacious belief in the technological capacity of science to “fix the problem” made it very difficult for community residents to appreciate two issues. First, even the best efforts to “fix the problem” cannot succeed in removing all of the asbestos from the community. Indeed, the tiniest particles of asbestos can only be viewed with specialized techniques such as Transmission Electron Microscopy (TEM).



Moreover, on a regular basis, new and unexpected particles of asbestos-contaminated vermiculite surface, even in places that have been cleaned multiple times. New pathways for exposure have also been identified through ongoing research. During the project's tenure, asbestos was found in tree bark and so residents who use wood for fuel might risk exposure to asbestos. So residents will, in all likelihood, continue to risk exposure to asbestos.

Second, there are no scientifically verified safe levels of exposure to asbestos. While the E-ABCs project was designed to translate scientific information for the community, only limited information is available. Scientists have debated whether the effects of tremolite, a type of asbestos prevalent in Libby, are more toxic than chrysotile, a more commonly recognized and studied form of asbestos. The EPA has not established a Reference Concentration (RfC) or a Reference Dose (RfD) for asbestos. As explained in a publication authored by the USEPA Office of Air Quality Planning and Standards (<http://www.epa.gov/asbestos/pubs/health.pdf>), the EPA uses mathematical models, based on human and animal studies, to estimate the probability of a person developing cancer from breathing air containing a specified concentration of a chemical. EPA calculated an inhalation unit risk estimate of 2.3×10^{-1} (fibers/mL)⁻¹. EPA estimates that, if an individual were to breathe air containing asbestos at 0.000004 fibers/mL(2) over his or her entire lifetime, that person would theoretically have no more than a one-in-a-million increased chance of developing cancer as a direct result of breathing air containing this chemical. Similarly, EPA estimates that breathing air containing 0.00004 fibers/mL would result in not greater than a one-in-a-hundred thousand increased chance of developing cancer, and air containing 0.0004 fibers/mL would result in not greater than a one-in-ten-thousand increased chance of developing cancer. This type of scientific information is difficult to apply when residents of a contaminated community try to assess personal risk.

In the face of scientific complexity and uncertainty, residents tend to embrace more intuitive perceptions of risk. They focus on scenic beauty, everyday events, and evidence of community improvements. They focus on the legal undertakings such as achieving compensation for those who have suffered from the exposure. They allude to sites where the clean-up is being pursued. There are discussions about priority areas for clean-up and the extent of abatement per household. Lurking behind the scenes is a question that few want to pose: Is clean-up really possible?

So though the work of the E:ABCs project has ended Libby's journey will continue. In the coming years, new science may provide new directions. Advances in healthcare may mitigate disease processes. But serious challenges remain for this community. So translation of scientific information requires a long term commitment. And Libby's story should be told for it can be instructive for other communities that face devastating environmental challenges.

