

HEALTH BEYOND MEDICINE

FIELD GUIDE FOR
EVIDENCE-BASED COMMUNITY-HEALTH PROJECTS



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Health Beyond Medicine: Field guide for evidence-based community health projects

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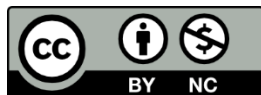
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Contents

Introduction

Chapter 1: Culture and Health

Chapter 2: Social Determinants of Health

Chapter 3: The Epidemiologic Transition

Chapter 4: Going Upstream:

Chapter 5: Environmental Health

Chapter 6: Evidence-Based Public Health

Chapter 7: Project Planning

Chapter 8: Simple Evaluation

Chapter 9: Communicating Your Message

Chapter 10: Social Action for Busy People

Chapter 11: Leadership

Chapter 12: Grant Writing, Fundraising, and Other Paths to Sustainability

Chapter 13: Behavior Change

Chapter 14: Global Community Health

Chapter 15: Health Systems

Chapter 16: Evidence-Based Happiness

Acknowledgments

Introduction



Amazing magazine cover: Frank R. Paul., Amazing: The Skylark of Space. Cover Illustration, jpeg. 1929, Public domain, via Wikimedia Commons. Accessed April 5, 2024 at <https://commons.wikimedia.org/wiki/File:Amazbuck.jpg>

Congratulations on having the kindness, courage, and commitment to learn about effective community action. Get ready for an amazing adventure. This manual will equip you to make the world a little better.

This handbook is very short. It is only a superficial summary of all the topics covered. Yet this material has a good track record, having led to many successful projects, including some that have become sustained community-level programs. Moreover, this curriculum has been successfully replicated at multiple sites across the country. Most importantly, participants have learned useful skills that they have taken with them into a variety of career settings.

This manual is unique in that it covers topics found in similar volumes, but with a different focus.

- *It's useful for designing programs from scratch, but ...*
 - ...it emphasizes **building on what is available off the shelf**, so that we can do more of what works, and less of what harms people.
 - So, if you are trying to increase school attendance by improving transportation, maybe you could organize a walking school bus instead of testing a bunch of experimental jetpacks.
- *It's useful for "social entrepreneurship" but ...*
 - ...it's based on **partnering with existing community-based organizations**, to avoid unnecessary competition and wasteful duplication of services.
 - It's nice to wave at community members as you float above them, but it might be better to talk to them first to find out what they think about your kids-with-jetpacks proposal. Maybe they have better ideas.
- *It's useful for enhancing medical care, but ...*
 - ...it addresses the other factors that affect health, like the social determinants, so we can start **moving upstream and prevent disease**.

-Jetpacks are an exciting potential way to move individual people around. But maybe you could take a step back and ask questions about inequities in transportation, and advocate for systemic solutions.

- *It's useful for getting projects started, but ...*

...it emphasizes using concepts from Dissemination and Implementation science, like first determining **feasibility and acceptability, and then pilot-testing** and debugging before taking things to full scale.

-Even if a deranged billionaire gives you an enormous grant to buy jetpacks for all the children, maybe you could try it out with an adult volunteer before you start fitting preschoolers for flight suits.

- *It's useful for doing research, but ...*

...it stresses that doing what works is more important than doing what's new. It shows how **evaluating relevant objective outcomes, especially from found data**, is the key for moving the needle on solving community level problems.

-You can measure how fast or light the fancy new jetpack is. But if it's not helping to reach the goal of increased school attendance because it's occasionally fatal so no one uses it, then fastness and lightness are probably irrelevant.

SCALE

For people who like rhyming mnemonics, the acronym SCALE might be helpful for remembering the five themes above.

Situate: Get the context. Look things up. Learn about what's already going on.

Cooperate: Contribute your expertise within a partnership.

Agitate: Social determinants are often best-addressed at a population level.

Levitate: Launch your project in stages, building on success step by step.

Evaluate: Verify that you are helping people and then share that info.

"SCALE" also reminds us that it's very important when starting a project to dream about how it could be scaled up—not because we care about making things bigger for the sake of it, but because we want to help as many people as possible. So, having a little project that works for 10 children in your neighborhood is nice, but replicating it for thousands or millions would be truly Amazing!

Illustrations

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Chapter 1

Culture and Health



Hôtel Dieu ["God's Hotel"] in Paris. Photo by xiquinhosilva from Cacau, Licensed under CC BY 2.0 <https://creativecommons.org/licenses/by/2.0/>, via Wikimedia Commons. Accessed April 1, 2024 at [https://commons.wikimedia.org/wiki/File:H%C3%B4tel-Dieu_de_Paris_\(36225162451\).jpg](https://commons.wikimedia.org/wiki/File:H%C3%B4tel-Dieu_de_Paris_(36225162451).jpg)

"Economists did the same thing with the other remedies of premodern medicine—good food, quiet surroundings, and the little things—treating them as expensive luxuries and cutting them out of their calculations. At Laguna Honda, for instance, while most patients were on fifteen or even twenty daily medications, many of which they didn't need, the budget for a patient's daily meals had been pared down to seven dollars, which could supply only the basics. I began to wonder: Had economists ever applied their standard of evidence-based medicine to their own economic assumptions? Under what conditions, with which patients and which diseases was it cost-effective to trade good food, clean surroundings, and doctor time for medications, tests, and procedures? Especially ones that patients didn't need?"

— Victoria Sweet,

God's Hotel: A Doctor, a Hospital, and a Pilgrimage to the Heart of Medicine

Cultural Concepts

My favorite definition of culture is that it's like **water around a fish**. The fish doesn't know it is wet. Similarly, culture is the set of beliefs and behaviors we share more or less automatically because that's what people in our culture do. Culture is what you're swimming in without realizing it. You only notice it when it's gone—like when you're traveling abroad. People are driving on the “wrong” side of the road, eating “disgusting” food, speaking a “foreign” language etc.

But the biggest cultural issue for most community health projects is the gap between the culture of academic medicine and the “real world.”

For example, in the book *How Doctors Think*, Harvard physician Dr. Jerome Groopman tells the story of a woman who adopts a baby in Vietnam. The little child gets very sick on the trip home and winds up hospitalized at a major teaching hospital with a diagnosis of “atypical SCID (severe combined immune deficiency).” Eventually, the mother—who is not a doctor—figures out that the baby has malnutrition, which is the most common cause of acquired immune deficiency in the world. By cleverly manipulating the doctors, she narrowly averts an unnecessary and potentially dangerous bone marrow transplant for the baby.



Photo by Andrew Aligne, with permission.



According to the Harvard physician, the moral of the story is that doctors have a hard time identifying “zebras” like malnutrition because they’re trained to look for “horses” like atypical SCID when they “hear



hoofbeats.” (Groopman 2008) This seems upside down to me. Malnutrition is a horse. SCID is a zebra. Atypical SCID isn't even a thing, so it's a unicorn. What's really going on in this story is **the culture of the academic medical center that is so far disconnected from the real world beyond its walls that it's easier to believe adamantly in unicorns than to see a horse in front of your face.**

Bridge from the Culture of Medicine to the Community

Stereotypically, the medical culture (especially academic medicine) is very hierarchical and competitive; the pace of activity is very fast; and diseases are viewed mainly as biological problems. By contrast, community-based organizations tend to be less hierarchical, with decisions made by consensus. The time horizon is more in months than in minutes. Health issues are viewed in the context of broad social and environmental factors affecting whole populations.

Ethnicity, race and class

In order to think constructively about culture and health, we need to be aware of the categories we use to describe people and to collect health data. Terms like Black, White and Hispanic are “loaded” and confusingly mix together concepts of ethnicity, race and class. Newer terms like African-American and Latinx clarify some matters while confusing others. It is

important to avoid assumptions based on stereotypes of ethnicities, cultures, races, or classes. It is crucial to understand “where people are coming from.” All that’s needed to start is to have an open mind and **accept that you may be operating with some assumptions** that are not the same as other people’s assumptions and that yours may not match with reality.

Ethnicity refers to a *self-defined* group of people who share a national, religious, linguistic and/or cultural heritage. For example, “Hispanic” is not really an “ethnicity.” The “Hispanic” or “Latinx” population is now comprised of a wide variety of people who might have very little in common, including different nationalities (Mexican-Americans, Puerto Ricans and Cuban-Americans), different religions (Roman Catholic, Evangelical Protestant, atheist), different languages (Spanish, English, Quechua), and different cultures (urban modern, rural, etc.). (Moses, Goodman, and Jones 2019)

Race is generally used to describe superficial phenotypic differences such as skin color. Race has little biological meaning with regard to disease causation. Nevertheless, the idea persists that race is related to disease. The examples that are given to support this idea are generally confusing race with geographic and cultural background. For example, sickle cell anemia is not a disease of “Blacks” per se, but rather a condition found in people of West African descent. In places where malaria is a problem, the hemoglobin S gene confers a selective advantage to heterozygotes. There are similar genetic adaptations that have arisen in other malarial areas, namely thalassemia in the Mediterranean and hemoglobin C in Canton. Some “White” Americans of Mediterranean ancestry have sickle cell anemia.

Most countries report health statistics by **class**, not race. The U.S. used to report health statistics by class but now emphasizes race. So, when you read, for example, that “Black children have more asthma than White children”, that’s true but it really means “poor American children living in inner-cities have more asthma than rich American children living in suburbs.” “Black” children in Africa have less asthma than “White” children in the U.S., so higher numbers of asthma patients are not likely to be caused by genetic “racial” differences between Blacks and Whites. (Aligne, Auinger, Byrd, and Weitzman 2000)

Community assessment tools

Assessment starts with just looking, listening, and caring. Beyond that are various approaches with different pluses and minuses.

- **A complete community needs/assets assessment.** This can take months or years and is beyond the scope of this manual. Usually, some kind of shortcut makes sense.
- **Partner.** I recommend partnering with a community-based organization that already has done a community assessment. So, for example, if you’re going to work on an asthma project, you would partner with the local asthma coalition and share in the information that they have spent years gathering. Some communities have resource guides of non-profits, either in print or online. Your local United Way for example might be able to connect you with local groups. You may have the 211 telephone and web help line in your area (311 in NYC). You could just

Google places and contact some names listed on websites but it's better if you can be linked from one real person to another. You can start by connecting to the community via whatever groups you already belong to, like clubs, associations, congregations, etc. Your local AAP chapter, for example, will often be an excellent resource for finding people active in community child health. Chances are you know someone who knows someone involved in whatever issue you're interested in.

- **Windshield survey.** This involves driving around a neighborhood and noting what you see. Depending on your issue of concern, you might count playgrounds or abandoned houses or liquor stores, or parking spaces. To be safe, you probably want to do this with at least two people so one can focus on driving. Or you could take a taxi or a bus. The advantage of this method is that it is fairly quick and easy; the disadvantage is that keeps you separated from people. It's a nice first step, but it rarely is sufficient.

- **Focus group.** There are two words in "focus group" and the first one is "focus." That is because focus groups work best when you have a couple of different ideas for interventions and want to determine which is most acceptable to a community. A focus group is not usually a great place to start when you haven't even really defined the problem, let alone the solutions.

- **Interviews** are more open-ended than focus groups but are time consuming and problematic. Also, the logistics of setting up interviews are often complex. Interviews are good for talking to someone who is self-identified as a spokesperson for a cause or organization. Self-identified spokespeople are reliably willing to talk but they aren't necessarily representative.

- **Written survey.** Internet-based surveys are even faster and cheaper than paper ones. But even in America, many people do not have internet access, and it's important to be inclusive when recruiting community-members to survey. Surveys may require more work up front than other methods of gathering information, but it's possible to keep things simple. Surveys should be very short and easy to read. I always include at least one open-ended question in any survey because that's where you get the richest information. This keeps the survey short while still allowing people who have a lot to say a chance to express it. If people are personally affected by the issue of concern and feel that you truly care, you will get a very high percentage returned. A survey I worked on in Senegal had a 100% response despite difficult conditions for administration in remote villages. The NGO running the survey, Netlife Africa, hired interviewers representing diverse ethnicities, languages, religions, etc. They visited all the villages before starting the survey to get permission. Netlife has distributed many thousands of bed-nets to save lives by preventing malaria, so they have a lot of local goodwill. The survey helped to reveal gaps that the program could then try to fill.

Follow-through

Why are you doing an assessment? The point should be to help people. Whatever community you work with is likely tired of various kinds of consultants, researchers, and students who "helicopter" in asking questions but then disappear without making a difference.

Implementing actual improvements is how you build trust with the community and allow for bigger stronger bridges to be built in the future.

And this process starts at the very beginning of your relationship-building with community members. First of all, you need to show up and keep showing up at their place and for their events. Without being their scut monkey, you should be helping them with their Good Work. You need to give them deserved credit for anything you do together. You need to keep listening in a give-&-take, so that you all stay on the same page. If you were to try to sum up this whole book in one word, it would be: **RELATIONSHIPS**.

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Illustrations

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Chapter 2

Social Determinants of Health



Swedish statisticians Anna Rosling Rönnlund, Hans Rosling, and Ola Rosling discuss their book "Factfulness" in 2016, Photograph, April 5th 2018, Gapminder Foundation, Licensed under CC BY 3.0 <<https://creativecommons.org/licenses/by/3.0/>>, via Wikimedia Commons. Accessed April 1, 2024 at https://commons.wikimedia.org/wiki/File:Anna_Rosling_Rönnlund,_Hans_Rosling,_and_Ola_Rosling_on_%22Factfulness%22.jpg

“...people tend to claim that certain values or behaviors are culture-specific, unchanging and unchangeable.

It’s just not true. Values change all the time.”

-Anna Rosling Rönnlund, Hans Rosling, and Ola Rosling

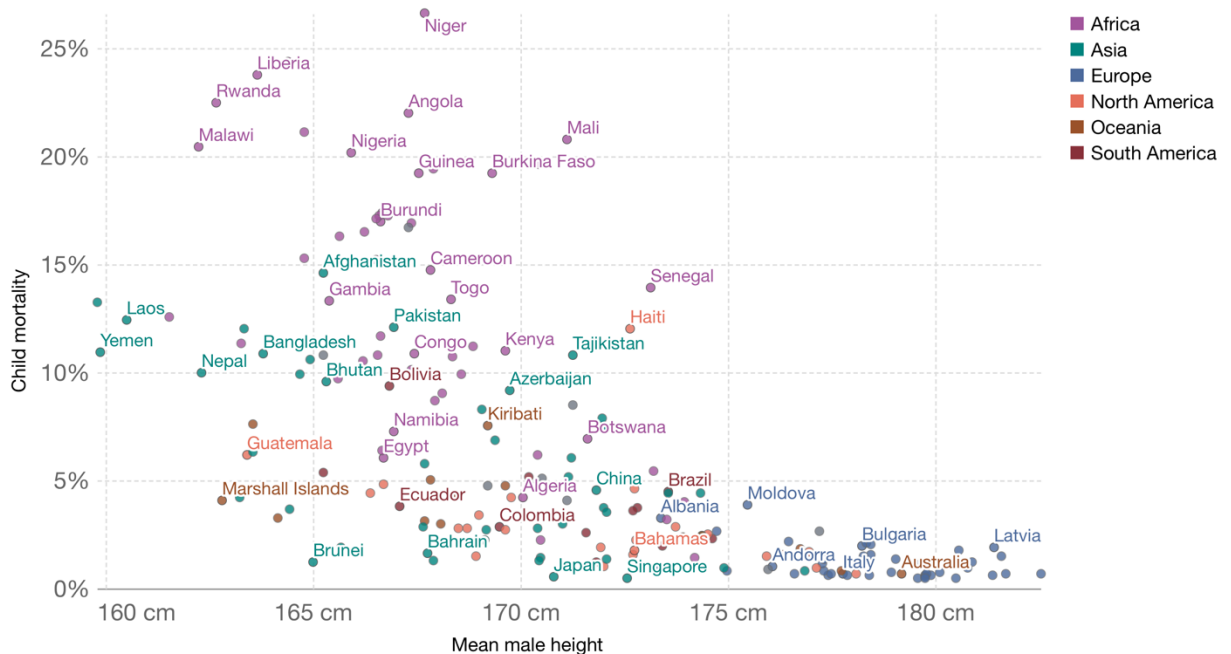
Determinants of Health

The Social Determinants of Health (SDH) has become a buzzword nowadays. But there's **a lot of confusion about what SDH means**. When I talk to medical students and residents around the country and ask them about what we can do to address SDH, they tell me about volunteering at clinics that provide free medical care. That is a good thing to do. I did that. Nothing against that. But it is sort of missing the point. To try to get to the heart of what SDH means, let's zoom out and look at some health statistics from around the world.

Child mortality rate vs. mean male height, 1996

Child mortality is defined as the share of children who die before reaching their 5th birthday. This is shown against mean height of adult men by year of birth.

Our World
in Data



Source: UN Inter-agency Group for Child Mortality Estimation (via World Bank), NCD Risk Factor Collaboration (2017)
OurWorldInData.org/human-height • CC BY

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Take some time to look at the graph above. There's a lot going on. On the vertical axis, you've got child mortality (the percentage of children who die before their 5th birthday). Overall, there are lots of dots, each representing a nation. We see quite a lot of variation in child mortality from around 1% in many European countries going all the way up above 20% in several African countries. We'll come back to that disparity later. For now, I want you to consider the relationship between child mortality and the other variable, average height.

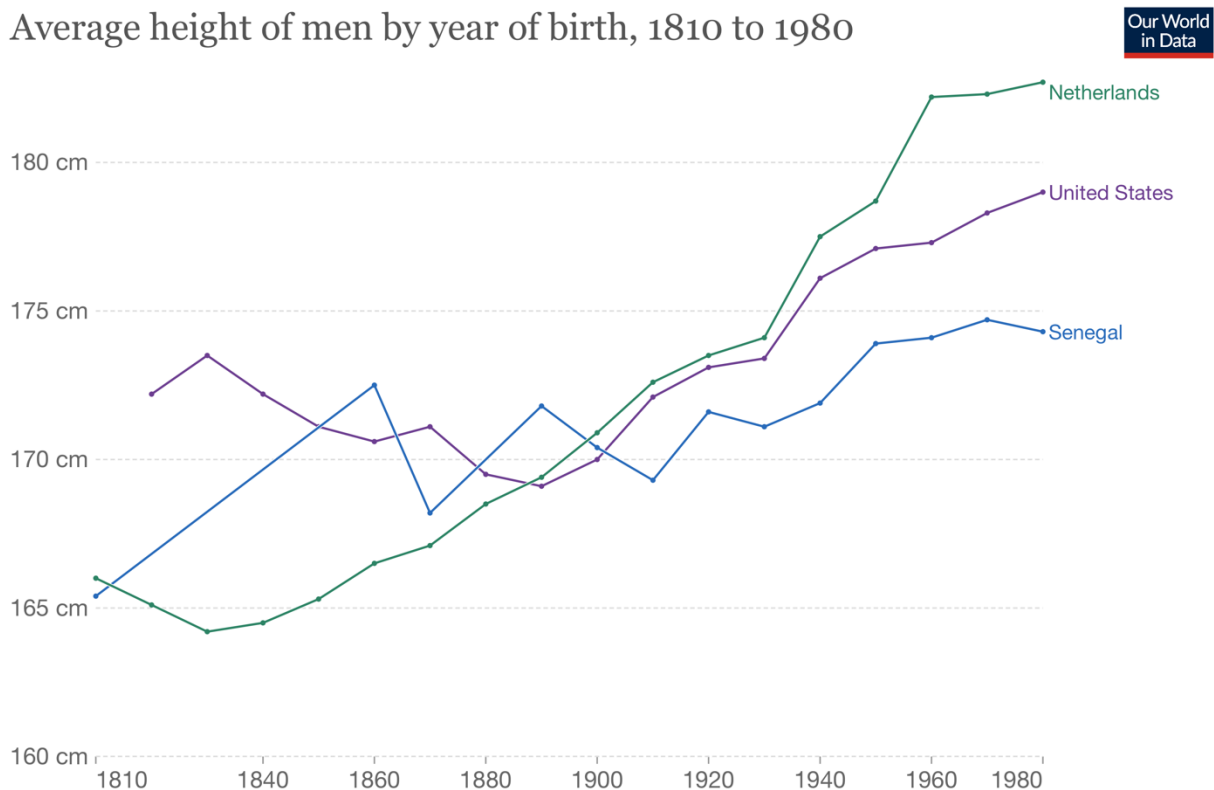
Average height by itself is a hard concept for some people. We're so used to thinking about individual patients as opposed to populations. But height is a simple objective measurement that's been recorded for a long time (e.g. among military recruits) so we have pretty good estimates of average adult male height for different countries. As it turns out, there's clear geographic variation in average height around the world, with the tallest

populations in European countries, and the shortest ones mainly in Asian and African nations. There are short people in Europe and tall people in Africa, but *on average* the European countries in the right tail of the graph are taller. If thinking about things like height for entire nations is new to you, then take a minute to let that sink in. Because being able to think about populations instead of persons is crucial for understand public health and for doing community projects.

Okay, let's get back to the point of the graph. **Overall, it seems like there's a correlation between shorter adults and more dead kids.**

Why is stature related to child mortality? The thinking among public health experts is that average height is a good proxy measure for the overall health of a population. So, the taller countries are generally better environments for people to live in. That health-promoting environment causes more people to grow to their full potential and it causes fewer babies to die. This concept may hurt your head as a physician, especially in pediatrics, where we are taught to think of short stature as a genetic disease treated with hormone replacement. To understand how height could be a marker of overall community health, it helps a lot to look at another graph.

Average height of men by year of birth, 1810 to 1980



Source: University of Tuebingen: Height datahub (2015)

OurWorldInData.org/human-height/ • CC BY

Adapted from figure found at Roser Max, Appel Cameron and Ritchie Hannah. *Our World In Data* website, <https://ourworldindata.org/human-height#citation> Accessed April 2, 2024. Licensed under CC BY 4.0. Data publisher's source: University of Tuebingen: Height datahub (2015) – processed by Our World in Data. "Human Height (University of Tuebingen (2015))" [dataset]. University of Tuebingen: Height datahub (2015) [original data].

Here, we're looking at height over time. To simplify, I included just three countries: ours, one of the European countries that beats us in height, and Senegal because it has statistics going back longer than other African countries. Overall, the graph is showing that height has been increasing over time in all these countries. That is broadly true as a global trend (for females as well). Comparing the trends for the three countries reveals some interesting divergences in these overall trends. The U.S. used to be much taller than the Netherlands, but that has not been true for a long time and the gap in favor of the Dutch seems to keep widening. Senegal at some points was the tallest but overall the curve has been pretty flat in the time period shown. (No, I don't know why it stops in 1980).

To me, the most curious thing about this graph is how the US curve dips down in the mid-19th Century, before turning up sharply around the turn of the 20th Century. This would suggest that the overall health of the US in the 1850s was worse than it has ever been either before or after. If that were true, we'd expect a peak of childhood mortality then, and that something happened by the 1890s to really turn things around. We'll check if that's correct later. For now, the big picture point is that **average height has changed a lot over time**. This kind of change over these short time spans is not readily explainable by evolution and genetic shifts. It suggests that human-induced changes in the environment are modifying basic physiological characteristics and influencing overall health.

The height distribution of a population is generally a bell-shaped curve. Some individuals are in the short tail-end, some are in the tall tail-end and most are in the middle. What we are talking about here is shifting the entire curve. Generally, the trend has been toward increased average height. This is clearly *not* because we have been injecting billions of people with expensive medications. There's some debate about exactly what leads to these kinds of shifts, but it's probably a combination of many factors including food, sanitation, housing, education, etc. That is to say, it's because of changes in society, i.e. social determinants of health. **SDH are, by definition, not bio-medical. SDH are the things beyond biology that make you sick, and the things beyond medicine that make you well.** The whole point of the concept is to go outside the bio-medical model when thinking about health and disease.

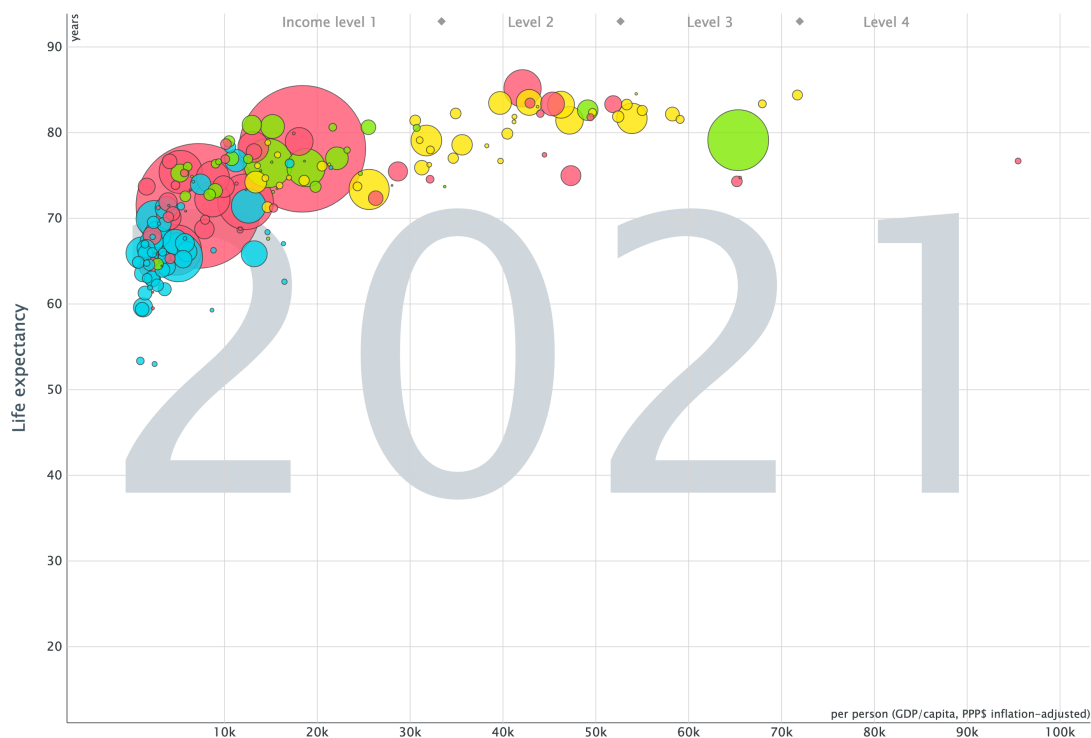
So, free medical care is nice, but medical care *per se* is addressing bio-medical determinants of health. It's not addressing the non-medical social determinants. Again, this may be hard to understand; if so, pause for a bit here. All this is confusing, in part because now that SDH has become a buzzword, it may seem like "screening for SDH" is the same thing as addressing SDH, but there is very little evidence for that. Also, it is easy to come up with arguments for how saving poor people some money by having them get treated by medical students could help fight poverty, but this is missing the point. The factors that make a whole population grow taller (and become healthier overall) are generally things beyond medicine. This is not to say that medical care is useless. It is important for physicians and other medical professionals to provide evidence-based, effective care that is proven to help individuals. Medical care is a part of improving population health. But it's not the only thing. It's not either/or, it's both/and. This handbook emphasizes the SDH/public health/community action side of things.

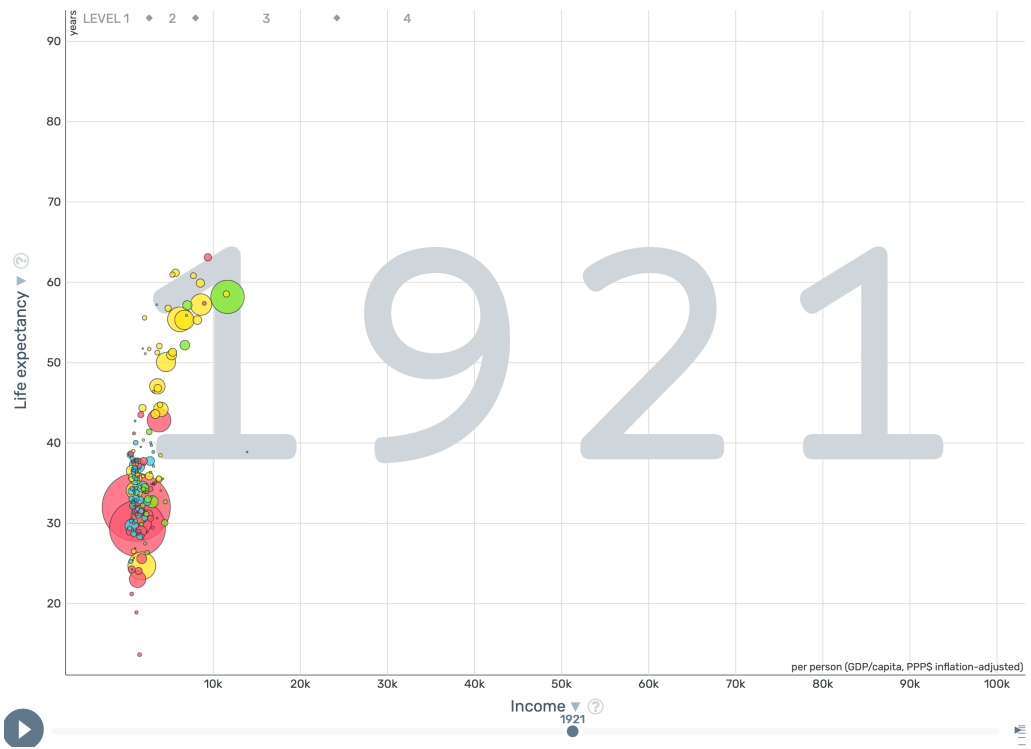
Risk Factors

If we look at the “major killer” in this country, heart disease, it is easy to see that there are factors other than strictly biomedical ones that affect outcomes. **When thinking about potential interventions for improving individual or public health, it is useful to focus on preventable causes, i.e. *modifiable* risk factors.** [There are economic, legal and philosophical objections to using the word “cause” when talking about things like cigarette smoking and heart disease, so instead it’s common to use the term “risk factors.”] Let’s consider heart disease, for example, since that is one of the biggest “causes of death” in the US. In the biomedical model, heart attacks are “caused” by things like high blood pressure, high cholesterol, clogged arteries, etc. In the public health model, it is “caused” by things like marketing of cigarettes and junk food, car culture, wealth inequality, etc. These are very different problems with very different solutions! (Stolley and Laskey 1998)

Looking at social risk factors, we can see that effective interventions may need to be occurring outside of the hospital or doctor’s office. One of the other salient points is that behaviors established before or during adolescence (smoking, overeating, inactivity, etc.) have an important impact on adult health. In other words, **improving health in adults means changing behaviors in children. In some ways, one can say, “everything is pediatric.”** Preventing underlying causes is called “going upstream.” We’ll talk about effective prevention more in later chapters.

Inequality





Figures above adapted from figure found at [https://www.gapminder.org/tools/#\\$chart-type=bubbles&url=v1](https://www.gapminder.org/tools/#$chart-type=bubbles&url=v1). Accessed April 2, 2024. Licensed under CC BY 4.0. Free material from www.gapminder.org.

Wealth is health? The two graphs in the figure above show life expectancy vs. *per capita* GDP in different nations around the world today and 100 years ago. As you can see, money today is a powerful predictor of health. The other key feature of this graph is that when wealth goes from zero to something, there is an enormous surge in health. But past a certain point (around \$30,000 on this graph) there is a plateau. Above that, a big increase in income only produces a small increase in life expectancy.

Looking at the graph from 1921, one sees that the change around the world has been astounding. (I recommend clicking through to the Gapminder website and watching the animation of the bubbles moving over time.) **This is one of the most important lessons of this book: things change!** People often avoid engaging in advocacy or related activities because they think that it's impossible to change things. But if you get a little perspective, it's easy to see that things change a lot all the time. 1921 is not ancient history—my father was alive then—and there were tons of countries where life expectancy at birth was under 30! Now there are none where it is under 50. In 1921, there were very few countries with a life expectancy above 60; now, it's almost all of them! This gigantic historical change in health is called the Epidemiologic Transition and we'll get into what caused it in the next chapter.

For now, the point is that poverty seems to be bad for health. But being below some income cut-off is not the whole story. Income is one component of Socioeconomic Status (SES), which is generally considered the most important social determinant of health. **SES is a complex concept** related to income, wealth, education level, location of residence, social status, etc. In general, low SES is bad for you.

Beyond absolute poverty, inequality is also bad for health: even in rich countries, people at the bottom of the social ladder tend to die younger than people at the top (Wilkinson &

Marmot). For example, in the famous Whitehall studies in England, where health data are collected by class, the risk of dying before age 64 is almost 4 times higher in low-level workers versus their bosses, even when they work in the same building, have the same medical care, etc. Research in animals and people has also shown that high social status is associated with objective biochemical markers of illness like “bad” cholesterol levels. So, “causes of disease” like high cholesterol that seem purely biomedical, may actually have underlying social causes. Inequality in the US is quite high vs. other rich countries. Social mobility is relatively low. The CEO-to-worker pay ratio in the US is over 300:1; in the 1950s and 60s, it was around 15:1. (EPI) SES factors like **poverty can contribute to poor health by altering living environments, or health behaviors, or even a person’s physiology, especially if poverty leads to lower social status and lowered perceived autonomy.**

In the US, it’s harder than in the UK to do something like the Whitehall studies because we don’t collect health statistics by class. We do collect statistics by race, and so race is often used as a proxy for class in health research. As we mentioned in the previous chapter, this is part of our American culture; it’s just what we do. But it is weird. Because race is not inherently connected to wealth--there are rich Black people and poor White people. Nor is race inherently related to most disease risks. Nevertheless, we do see big health disparities by race, so there is some kind of connection between race and health in the US. The current thinking on this is that the issue is not race, but racism.

Racism in America has been used to divide the powerless of all races against each other (Mc Ghee). This is beneficial to those who are already on top of the power hierarchy. The consequence is increased inequality overall, but with magnified inequities for members of the stigmatized races. These inequities then influence one’s neighborhood, educational background, and social network. As a result of centuries of virulent racism, there are systematic differences in the lived experiences of “Blacks” and “Whites” that persist today. For example, the median household wealth of Blacks is about 10 times lower than that of Whites (Bhutta 2019). And wealth is probably more important to look at than income when measuring SES. Studies that control for income but ignore wealth are not really controlling for SES. Again, this is a point where it’s important to think in terms of population averages instead of looking at individuals. Yes, Oprah is mega-rich, and yes, someone reading this has a White uncle who’s broke. But that doesn’t change the big picture of the situation for millions of people. The historical effect of racist policies and practices in the US is undeniable.

Racism clearly has had an impact on SES disparities, but Blacks in the U.S. experience worse maternal and infant mortality than Whites *even after controlling for SES*. (Matoba and Collins 2017) This is thought to be an effect of living in a racist society, where incessant stigmatization can cause chronic distress for U.S. Blacks with all the resulting physiological consequences. This chronic stress has been labeled “weathering.” (Geronimus 2023) It’s not something that can be undone simply with a cash payment or a pill. Thus, **the health impact of racism goes beyond wealth or access to medical care.** This is important to understand for trying to do something about problems like racial disparities in infant mortality and maternal mortality. If these are the result of processes happening long before a woman becomes pregnant, then effective remedies may need to happen before prenatal, obstetric, or neonatal care even begin. In the biomedical paradigm, we try to solve every health problem with more medical care, but that is not always the right tool.

As it turns out, there are population-level approaches for decreasing infant mortality. Research abroad suggests that maternal literacy is a major determinant of child health and that **educating girls is the most effective way to decrease infant mortality**. In the table below, what correlates better with infant mortality: literacy or GDP?

Infant Mortality Rate, Female Literacy, and GDP in India, Selected States

<i>State</i>	<i>Infant Mortality Per 1,000 Births</i>	<i>Female Literacy (Percent of Population)</i>	<i>State Gross Domestic Product Per Capita (in US dollars)</i>
Kerala	52	64	96
Karnataka	81	28	99
Maharashtra	94	35	139
Uttar Pradesh	181	14	60

Table adapted from data found in: Sagan, Leonard A. 1987. *The Health of Nations: True Causes of Sickness and Well-Being*. P. 178. New York: Basic Books. Data source: United Nations, *State of the World's Children 1984*, p.150. New York: Oxford University Press, 1983.

The high female literacy in Kerala was a direct result of programs implemented as a part of efforts to improve the health of the people there. **One of the lead theories for how increasing maternal literacy increases infant health is that it raises the mother's sense of personal power starting when she is a little girl.** In particular, it helps her to control her fertility (how many children she decides to have). This in turn is part of a **positive feedback loop** that feeds growth in the local economy. Increasing literacy can increase health, which can increase wealth, which can increase health more and so on. So, literacy enables a mother to take better care of herself and her children because she can read about immunizations and whatnot. But it's more than that. The weathering research in the US indicates that the relatively high Black infant and maternal mortality in the US come from a lifetime of accumulated disempowerment in the mother. Increasing the mother's sense of personal power beginning in childhood sounds like a potential remedy.

I'm not saying you should jump from the Kerala experience to a new program in your neighborhood. My point is that you probably never heard of it before, even though it's this amazing intervention for saving baby's lives. And maybe somebody is considering it here, but having read books and gone to meetings for years on this topic, what I keep hearing about is enhancements to treatments that start after pregnancy. I think it would be good to broaden our paradigm. After all, illiteracy is a huge problem in the US, especially for poor, Black children, so what would be the harm in improving literacy? Why aren't ideas like this part of the conversation?

Medical treatment is important. But medical treatment already dominates our health system and gets plenty of attention. So, I think it's fair in this little handbook to emphasize SDH and the many big-picture factors that also have a giant impact on health. If you are addressing SDH effectively, people are healthier and don't need as much medical care. Is that not a good goal?

Note: Science!

There's a reason I include graphs and charts and talk about studies in this manual. Public health is science. Epidemiology is science. Science is not limited to biology experiments. People in medicine too often use "science" to mean only stuff that happens in a laboratory. That is a narrow viewpoint. The essence of the scientific method is the testable hypothesis (leaving aside philosophical debates about knowing vs. Knowing). "Is illiteracy correlated with infant mortality after adjusting for potential confounders?" is a testable hypothesis. "Does teaching children to read improve intergenerational health outcomes?" is a testable hypothesis and even a potential randomized trial. We know stuff about SDH and risk factors. We know stuff about how to save millions of lives. Why not use that evidence base?

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Chapter 3: The Epidemiologic Transition: From Diseases of Lack to Diseases of Excess



Unknown Photographer, *Elizabeth Blackwell*, Photograph, 1928, Public domain, via Wikimedia Commons. Accessed April 5, 2024 at <https://commons.wikimedia.org/w/index.php?curid=679520>



Perry Pictures, *Florence Nightingale, pioneer of modern nursing*, Photomechanical print, 1920, (Library of Congress: Prints and Photographs Division Washington D.C.), Public domain, via Wikimedia Commons. Accessed April 5, 2024 at https://commons.wikimedia.org/wiki/File:Florence_Nightingale_1920_reproduction.jpg

Elizabeth Blackwell (1821 – 1910) was a British and American physician, notable as the first woman to receive a medical degree in the United States, at Geneva Medical College in Geneva, NY.

Florence Nightingale (1820 – 1910) was an English [social reformer](#), statistician and the founder of modern [nursing](#).

“One of my most valued acquaintances was Miss Florence Nightingale... To her, chiefly, I owed the awakening to the fact that sanitation is the supreme goal of medicine, its foundation and its crown.”

-Elizabeth Blackwell

Do We Live Longer Now?

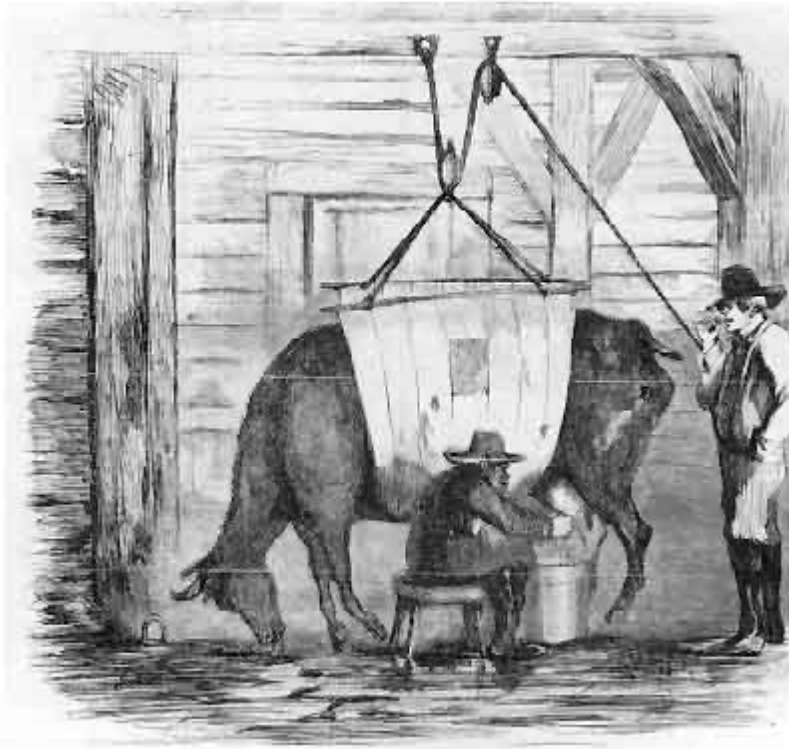
Average life expectancy at birth is much longer now than it was 200 years ago. That is true. What we hear all the time is that “people live longer” because of the “miracle of modern medicine” whereby advances in basic science have led to new technologies that allow us to rescue people from the jaws of death. This is somewhat misleading. Remember those Gapminder animations from the last chapter? Around 1890, life expectancy in the US goes up almost vertically. At the same time, child (0-5 year-old) mortality zoomed down! Child mortality in the US was around 330/1,000 in the 19th century. In places like New York City in the 1850s childhood mortality was above 50%. That means it was common for children not to make it till their 5th birthday! **Imagine a world where half the people die around age zero and half die around age 70. The average life expectancy at birth would be 35** – not because most people died around age 35 but because so many young children died.

If this seems hard to believe, think back in time 250 years ago, before the invention of any of the effective modern medical technologies we have today. Benjamin Franklin, Thomas Jefferson, John Adams and such were not all dropping dead when they were 35, and it was not considered miraculous that they lived past 70. George Washington did not make it that far, but historians think it's in part because of harmful “treatments” like massive bloodletting that he received from his doctors (Markel). Nevertheless, the idea that “nobody lived past thirty” in the past is very deeply ingrained in our culture’s conventional wisdom. So, it’s totally understandable that you believed it too. **Our population on average is older, but it’s not because medical miracles gave us “an extra life” so that people used to die at age 35 and now live to age 70.**

The world before 1890 was not full of withered 35-year-old grandparents dropping dead in their tracks. Life expectancy AT BIRTH has increased tremendously *mainly* because children don’t die anywhere near as much as they used to. Another reason the population is older on average is that people have fewer children than they used to: the proportion of old people in the population (and therefore the average age) increases from that even without anyone living longer. Since immigrants tend to be young and to have children, decreasing immigration will also increase the average age. Additionally, there are more old people around just because the total population has increased. **So, “we live longer” is confusing. The real deal is that we are more likely to survive childhood.**

Sanitarian Movement

What happened to make childhood so much less dangerous? A big part of the story is



Frank Leslie's Illustrated Weekly, 1838, A 19th Century illustration of "swill milk" being produced: a sickly cow being milked while held up by ropes, Newspaper, Public domain, via Wikimedia Commons. Accessed April 5, 2024 at <https://commons.wikimedia.org/wiki/File:Swillmilk1.jpg>

about **swill milk**. In 1800s New York City, a major cheap source of nutrients for children was cow's milk. Most of the year, this was okay. But in the summer, the milk tended to spoil because it took several days for it to get to the city from farms. To try to get around this problem, entrepreneurs set up urban dairies at distilleries, where the cows were fed grains left over from making whiskey. This is not an ideal environment for bovines, and these cows were so diseased (or drunk?) that they couldn't stand up and had to be raised off the ground with pulley-sling contraptions.

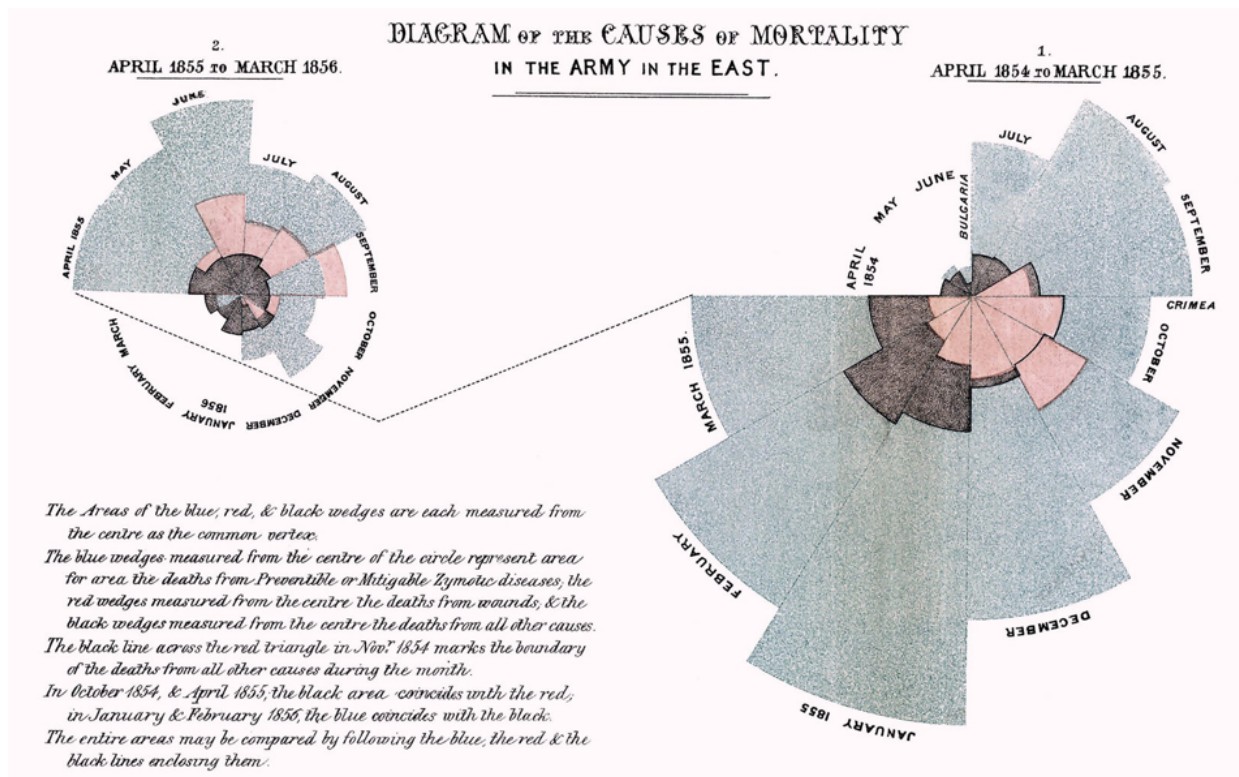
Then, the pus-filled milk from these filthy cows would go into filthy buckets, which were then poured into filthy barrels for the market where it got ladled out into jugs. Along the way, to make more money, the merchants would dilute the milk with filthy water and then add white chalk and dirt to make it look like milk. This disgusting beverage was known as "swill milk." Every summer, many children were dying of dysentery. It was not subtle. People understood it was from the milk. One children's home even did a controlled demonstration, giving some kids dirty market milk and other kids clean milk. The kids who got market milk died much more often. The Milk Problem became a political issue and there was public will to clean up the filthy milk. There were many partners in this effort including journalists, social reformers, orphanages, and parents.



Frank Leslie's Illustrated Weekly, 1838, A 19th Century illustration of "swill milk" being produced: a sickly cow being milked while held up by ropes, Newspaper, Public domain, via Wikimedia Commons. Accessed April 5, 2024 at <https://commons.wikimedia.org/wiki/File:Swillmilk1.jpg>

Among the leaders in the **Pure Milk Movement** were Nathan Straus, the co-owner of Macy's department store, and Dr. Abraham Jacobi, the founder of pediatrics in the US. Jacobi's slogan was "No raw milk! Boil the milk until it bubbles." Before pasteurization, this was not a bad idea, but boiling milk at home was not a very practical solution for poor families in the summer. Straus's approach had more success.

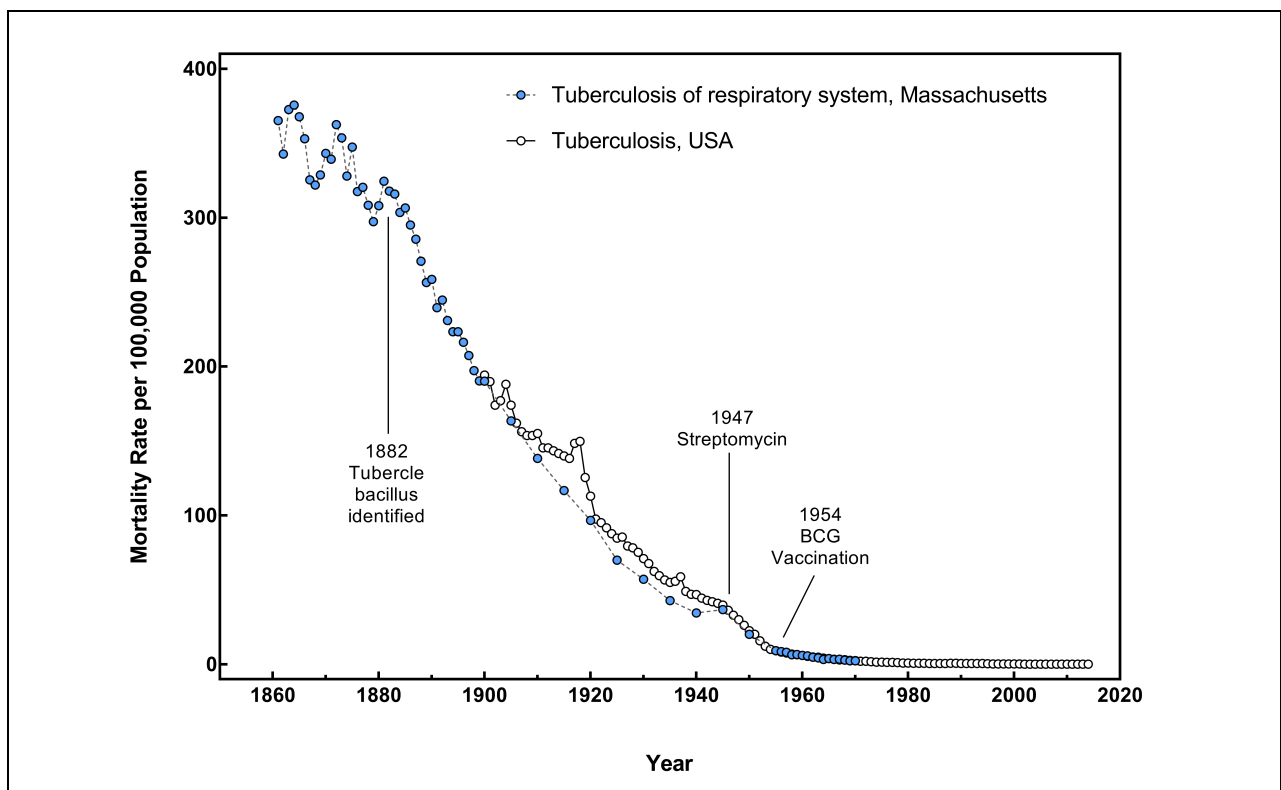
Beginning in the 1890s, Straus was a financial backer of milk stations, which provided free sterilized milk for children. These stations lasted for decades and were very important but could never reach more than a limited number of people. To get to scale, it was necessary to enact reforms that changed the whole system of milk production. Procedures were put in place to inspect market milk and make sure it didn't contain visible dirt. This was the origin of 'Grade A' milk. Eventually, pasteurization also became standard nationwide. A research paper from 2007 looked at how important it was to get rid of the swill milk. It concludes that ***"cleaning the market milk supply was the single most important contributor to the decline in both diarrheal and overall infant mortality."*** (Lee 2007).



Swill milk was just one chapter in the bigger story of the Sanitarian Movement. One of its guiding lights was Florence Nightingale. She was one of the founders of professional nursing and in addition to that was one of the great innovators in public health science. She documented and diagrammed the causes of death among soldiers in the Crimean War, determining that infections were a bigger problem than injuries *per se*. She then enacted reforms that dramatically increased survival. She showed that things like nutrition, cleanliness and ventilation were of key importance. This helped establish the effectiveness of **fighting filth to improve health**. It's fashionable now to mock the Sanitarians because they believed that stinky odors caused disease (Miasma Theory). We know now that they were wrong in their theory. Nevertheless, the actions inspired by Miasma Theory—like sewers and clean water systems and pure milk—saved many millions of lives. I would rather have a silly theory with great outcomes than a beautiful theory that kills people. Wouldn't you?

The Role of Medicine

Now that you understand that much of the increase in life expectancy is due to decreased child mortality, you might ask how much of that was from medical vs. non-medical factors. Vaccines, antibiotics, and NICUs have had an effect, but the impact is small compared with the dramatic drop in mortality that occurred before the invention of these technologies. Many major infectious scourges largely disappeared before the existence of antibiotics or modern immunizations. **Overall, there has been a major shift from acute infectious diseases (especially affecting children) to chronic non-infectious diseases (affecting mainly adults). This shift is called the Epidemiologic Transition.** According to Dr. Thomas McKeown, this represents **a shift from “diseases of lack” to “diseases of excess”** (McKeown 1988). Infectious diseases are related to lack of food, housing, sanitation, etc., whereas chronic diseases are related to excesses of food, drugs, labor-saving devices, pollution, etc. In this paradigm, the best way to decrease sickness in low-income areas is to help decrease things like malnutrition, and the best way to help in rich areas is to decrease things like junk food, etc. Nowadays, many populations suffer from lack and excess simultaneously, for example crowding and cigarettes. On a population level and historically, medical care has not made as much of a difference as addressing Social Determinants of Health.



Tuberculosis deaths over time in US

McKeown, Thomas, *Merged mortality rates of 'tuberculosis of respiratory system' in Massachusetts 1861-1970, and 'tuberculosis' USA 1900-2014*, Graph, 2016, CC BY-SA 4.0
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Let us look at tuberculosis (TB), as one example of a major infectious disease. I could have shown similar graphs for measles, whooping cough, pneumonia, etc. (Just to make the point that I'm not cherry-picking, there are exceptions like polio, but I can't get into the details of that here.) TB mortality is on the decline by 1860 or earlier. This is before the germ is identified. The steep steady drop-off starts around 1890, which is long before the development of an antibiotic (Streptomycin) or a vaccine (BCG) for TB. Lawyers and philosophers can tie you in knots trying to define "causality", but it seems safe to say that causes have to exist before effects.

Vaccines are amazing! Antibiotics are amazing! Modern medicine is amazing! But something else is going on in the graph above to explain the enormous historic decline in TB. Whatever that something is, it's an order of magnitude even more amazing than medicine. Academicians argue about whether food safety, or housing, or sewers, or general economic development mattered most in the Epidemiologic Transition. I honestly don't care; I just lump those all together as SDH. The mind-blowing point is that it was not medicine. **Again, this is not either/or. I love Germ Theory, vaccines, and all that. I'm only suggesting that when dealing with community health we should pay attention to community-level actions.** Part of the reason advanced medical care plays a small role relative to other factors is that it reaches a relatively small portion of the population at any given time. Medical experts have a skewed perspective because they "live" in the academic medical center with unicorns and zebras.

Some observers have even suggested that medicine may do more harm than good at a population level; medical error is one of the leading causes of death in the U.S. (Illich, 1975; Makary, 2016). Medicine matters, but some of the most impactful medical interventions like smallpox vaccine are cheap and simple enough that a physician is not needed to administer them. Among programs to improve health, medical care is only one of several. There is tremendous value to modern evidence-based and compassionate medicine. **The point of discussing the role of medicine is just to realize that the public health approach is crucial. Community health action is not just "touchy feely" and "soft" as opposed to "hard science" and clinical medicine. In fact, it's been the most important force moving the needle on health statistics, including "hard outcomes" like mortality. So, do not let anyone make you feel bad for wanting to do good work in the community.** If you understand the material in this chapter, that's amazing. Just this bit of knowledge has profound implications for Medicare, Social Security, public health, health system planning, etc. It involves grasping complex duality concepts like prevention/treatment, population/patient, outliers/averages, anecdotes/evidence, history/now, geography/here, etc. You already know more than all the journalists, politicians, writers, and other so-called experts I hear all the time talking about "the amazing increase in lifespan" and how "everyone used to die at 30." **YOU ARE THE EXPERT!** Your understanding of community-level factors is valuable and can make a real positive difference.

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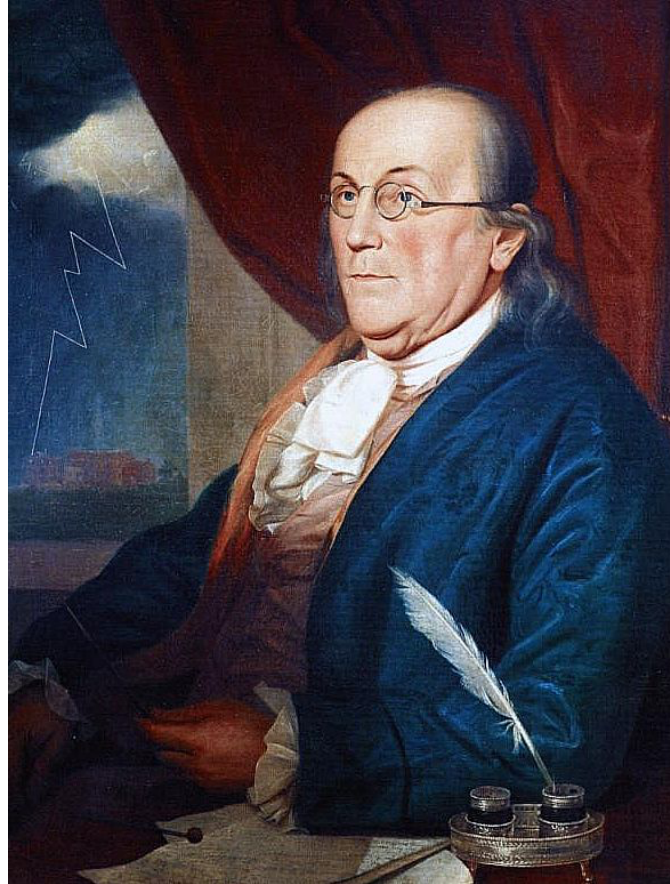
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Chapter 4

Going Upstream –

How to start thinking about health problems before designing a project



Portrait of Benjamin Franklin, ca. 1789 by Charles Wilson Peale, Public domain, via Wikimedia Commons Accessed April 2, 2024 at https://upload.wikimedia.org/wikipedia/commons/c/cc/Benjamin_Franklin%2C_by_Charles_Wilson_Peale.jpg.

“An ounce of prevention is worth a pound of cure.”
--Benjamin Franklin

Upstream/Downstream parable

A young physician is on vacation in a secluded forest. She is walking along a riverside contemplating the beautiful scenery when she notices somebody in the river being carried along by the current, flailing about and apparently on the verge of drowning. Having recently learned CPR and assorted other lifesaving skills, she enthusiastically jumps into the river and with great difficulty manages to pull the drowning person out of the river, carry him to safety on the shore, and resuscitate him. As soon as she ascertains that he is safe, she sees somebody else flailing about in the river, jumps back in, and pulls the other person to shore. Unfortunately, this keeps happening. After she has rescued about 20 people, the first one starts to wake up and can tell her what happened. She learns that all these people have fallen through a hole in the bridge that crosses the river chasm somewhere upstream from her



location. As it gets dark, people stop coming down the river. She can go find a park ranger who puts up a barrier either side of the bridge to keep people off of it until it can be repaired.

The moral of the story is that even though it was very thrilling to be engaged in the heroic activity of saving all those people from the raging river, it would have overall been a lot better for everyone if someone had started upstream by eliminating the danger of falling through the hole in the bridge, rather than waiting for people to be downstream drowning. This story provides a useful lesson for engaging in community health projects; one should always ask before implementing an intervention if it is possible to go further “upstream”. **People in CBOs use “upstream” and “downstream” all the time. To communicate with them, you need to know their language.**

Levels of Prevention

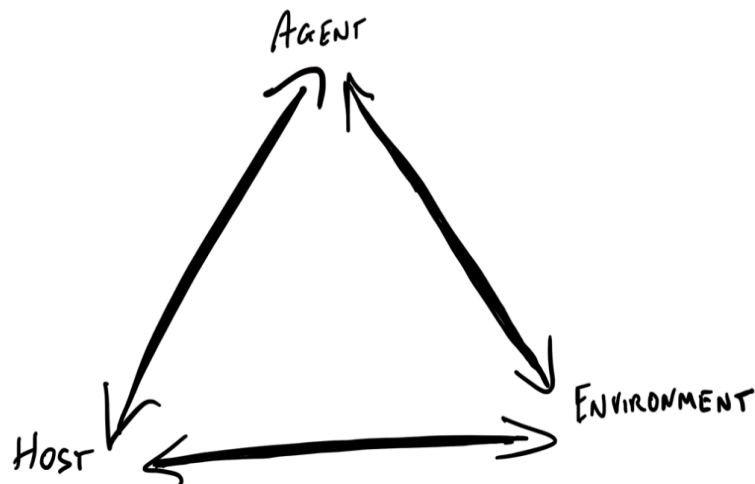
- I. **Primary prevention** involves preventing a disease before it occurs so that healthy people stay healthy. Examples of this include immunization, fluoride supplementation, etc.
- II. **Secondary prevention** involves prevention of morbidity, mortality, and disability in people who have a disease before they are affected by its consequences. Examples of this include newborn blood testing for phenylketonuria, vision screening for refractive errors, etc.
- III. **Tertiary prevention** involves assistance to people who already have suffered from a given disease in order to prevent further suffering or limitation from occurring. Examples of this include physical therapy after a traumatic brain injury, psychiatric counseling for victims of abuse, intensive case management for diabetic patients after hospitalization.

While even the tobacco industry accepts that an ounce of prevention is worth a pound of cure, **our health system is heavily biased toward cure**. When we do talk about prevention, it's often tertiary prevention. For example, in recent years, there has been a lot of talk about ACEs (Adverse Childhood Experiences) and how trauma in childhood can cause adult disease. The remedy suggested is to train people who work with children to be "trauma-informed" with the idea that we can help mitigate some of the damage. That is great, but wouldn't it be even better to keep those kids from being traumatized in the first place?

The Epidemiologic Triangle

We keep acknowledging the non-medical SDH but then trying to fix them with medical care. Ever since Louis Pasteur & Robert Koch developed the Germ Theory of disease, the **doctrine of specific etiology** – i.e. the idea that specific diseases have specific biological causes, has been the central dogma of Western medicine. (Dubos 1987) Specific etiology has been a constructive force in medical research for over a century. It has led to many of the theoretical and practical achievements that constitute the bulk of modern medicine. Yet, the search for a single biomedical cause may be counterproductive when diseases are caused by many factors.

Even for infectious diseases, focusing on just the infectious agent misses a lot of the picture. One way to think about this is to say that "influenza alone doesn't cause the flu." Influenza is everywhere each winter, but only some people, under certain conditions, will become ill after exposure to the virus. Thus, the virus (agent) is causing the infectious disease, but so are problems with the patients (host) and their life conditions (environment), especially if you are talking about very big problems like epidemics. This concept is illustrated by the "Epidemiologic Triangle." Note that the three components interact with each other.



The standard biomedical model focuses on the agent corner of the triangle. The role of the agent is real, but it's not the whole story. The biomedical paradigm is limiting. **In the swill milk story, nobody ever figured out the specific etiologic agent of the deadly dysentery. The sanitarians did primary prevention and saved millions of lives by cleaning up the environment and changing host behaviors. They did this without specific treatments for specific germs.** Again, antibiotics and vaccines are wonderful. But they are not the only tools in the toolkit for improving health. "If all you have is a hammer, everything looks like a nail." You have more than a hammer. Expand your paradigm.

The epidemiologic triangle works for non-infectious diseases too. Consider the number-one killer in the United States: heart disease. The way we usually think about it is that the cause is the specific biological “agent” of cholesterol plaques clogging arteries. But once we broaden our framework, we can quickly identify many other causes at the level of host and environment. One way to get at the upstream or root causes of a problem, is to use the **“But why?”** technique, which simply involves asking the question “But why?” after stating a problem, until a satisfactory answer is generated. For example, there is a lot of heart disease in America. But why? Because people eat a lot of junk food. But why? Because of Big Junk... The great thing about dealing with root causes is that you can take care of a whole swath of problems all at once. For example, successful positive youth development programs decrease school dropout, and teen pregnancy, and violence, among other metrics.

ANALYZING ROOT CAUSES OF PROBLEMS:

- The “but why?” technique

“Root causes” are the basic reasons behind a problem

- FIXING ROOT CAUSES
SOLVES MULTIPLE
PROBLEMS AT ONCE



Shifting the Curve

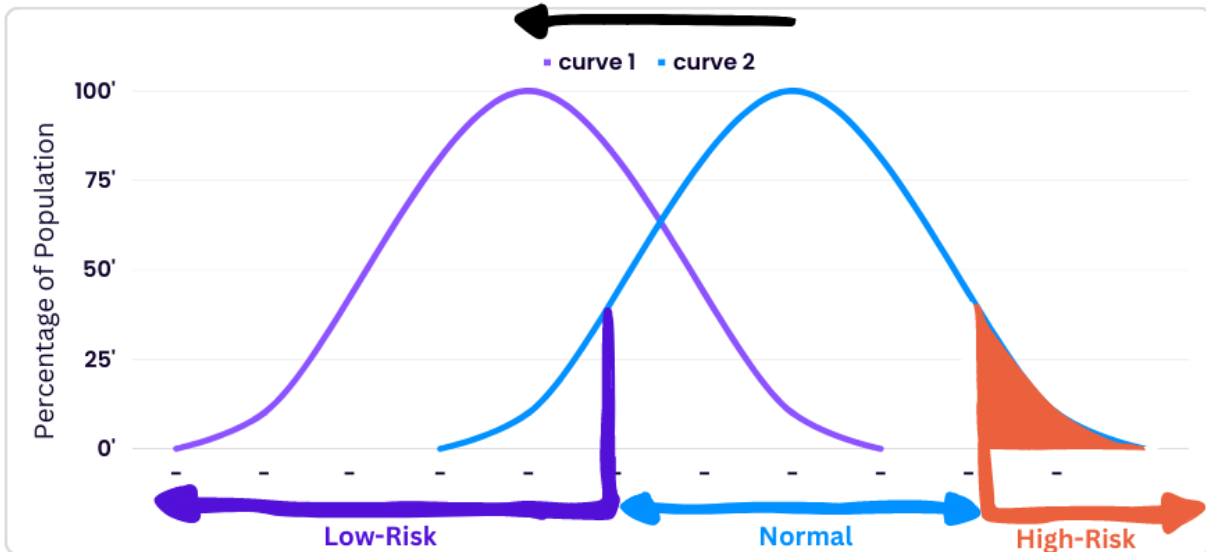


Figure is original art for this book by Andy Aligne and Maddie Rice, based on concepts in Rose's *Strategy of Preventive Medicine*.

In the figure, we're looking at what prevention expert, Dr. Geoffrey Rose calls "shifting the curve." *"A large number of people at a small risk may give rise to more cases of disease than the small number who are at a high risk."*

Some of the difficulty in evidence-based community health is that it is often difficult to think at a population level instead of at an individual level. **It can be much more efficient and effective to act at the level of the whole population than to focus on the extreme cases in the tails.** Without doing anything specific for lead-poisoned children you can eliminate millions of cases of bad outcomes by implementing a general preventive intervention that makes a small change for the whole population, by taking lead out of gasoline. That happened.

In the Hoekelman Center now, we're working on emergent literacy. If we can help more children to be ready for kindergarten, we should decrease the scarcity of "special ed" in K-12 education by decreasing the need without increasing the services. **Decreasing the demand helps services get to scale without increasing supply.**

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Chapter 5

Environmental Health



U.S. Fish and Wildlife Service, *Rachel Carson Employee Photo*, Photograph, 1940, Public domain via Wikipedia:
https://en.wikipedia.org/wiki/Rachel_Carson#/media/File:Rachel-Carson.jpg, accessed April 1, 2024.

*“How could intelligent beings seek to control a few unwanted species
by a method that contaminated the entire environment
and brought the threat of disease and death even to their own kind?”*

— Rachel Carson

Rachel Carson’s book *Silent Spring* helped to launch the environmental movement in America. One of the impacts of the book was that the pesticide DDT was banned in the US. This was done in part to save bird species that seemed to be harmed by the widespread outdoor spraying of DDT. Critics of the book say that DDT was essential for controlling malaria and so banning DDT contributed to human deaths. Actually, malaria control mainly happened long before DDT. Anyway, this chapter is about how to approach dealing with environmental dangers.

How do we know if an environmental exposure is causing health problems?

This is a question that comes up a lot. Fortunately, there's a general approach to determining causality in epidemiologic research, and it doesn't involve any difficult math. I am talking about the criteria developed by Sir Austin Bradford Hill in the 1950s to "prove" that cigarette smoking "causes" lung cancer.

If you are a corporate lawyer defending an industry that kills people, then you might say that it's pretty much impossible to "prove" that anything "causes" anything and that epidemiology is basically worthless. Okay, sure. At some level, no one can really know anything because you, dear reader, could just be my fever dream and not really exist. But if that's true then discussing any topic is pointless, so you should stop wasting your time on "knowledge" and run away right now.

Still here? Good.

So now, let's look at something not as settled as cigarettes and cancer.



HILL CRITERIA

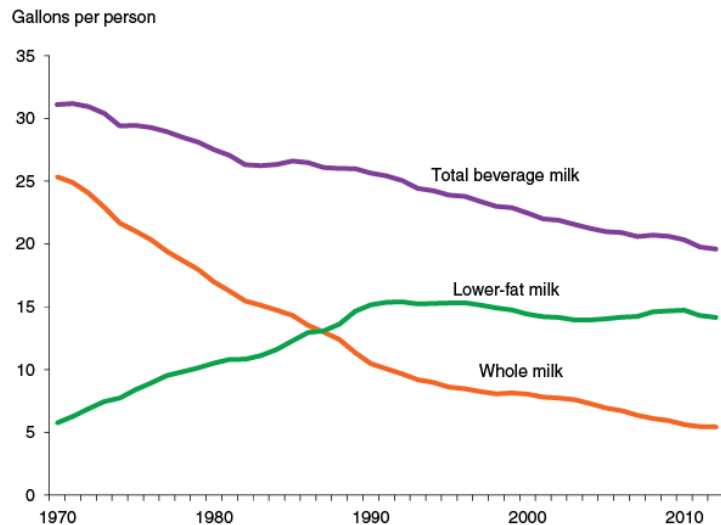
To illustrate, let's apply the Hill criteria to test if passive smoking causes asthma in children.

- 1 Geographic Distribution**
There is smoking where the disease is: Many children in the USA and almost all inner city children (where asthma is worst) have measurable environmental tobacco smoke (ETS) exposure. There is no smoking where the disease is not: Papua: no smoking, no asthma.
- 2 Temporal Association**
This is difficult to show for chronic diseases. Asthma exacerbations are not clearly associated with specific single exposures. It is easier to look at discrete events after a well-defined duration of exposure: Neonatal effects are clearly associated with smoking during pregnancy.
- 3 Biological Plausibility**
Tobacco smoke contains many substances known to cause disease in humans or animals. Parents expose their children to secondhand smoke components not only via their respiratory system, but also via breast milk and prenatally across the placenta.
- 4 Controlling for Other Factors**
Age, Sex, Race, SES, Medical history, Environment, etc. The relationship between smoking and asthma persists after adjusting for all of these.
- 5 Biological Gradient**
There is an increased likelihood of asthma with increasing exposure to tobacco smoke.
- 6 Experimental Exposure Causes Disease**
Exposure to tobacco smoke increases cotinine and can precipitate asthma attacks.
- 7 Case-Control Studies**
Children with asthma are more likely to have been exposed to ETS.
- 8 Cohort Studies**
Those with exposure to ETS are more likely to get asthma.
- 9 Clinical Trials**
Asthma symptoms are reduced or eliminated by decreasing exposure of asthmatic children to ETS, for example by moving them to boarding schools in the mountains.
- 10 Consistency and Coherence of Data**
Studies of different types over many years from all over the world leading overall to the conclusion that ...ETS causes asthma suffering.

Figure is original graphic design by Minhtam Tran for this book, with permission.

The obesity epidemic.

Here are some risk factor time trends. The following graphs are based on USDA data and

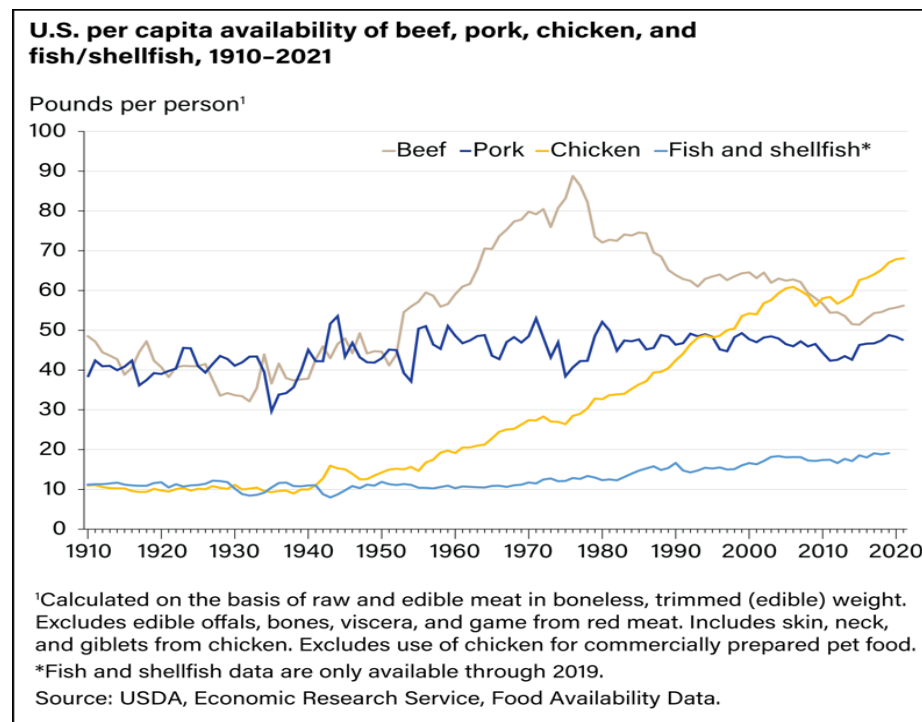


describe trends in what Americans have been eating since 1970. This is an interesting time window to look at for trying to understand the obesity epidemic, which takes off in the 1980s. **On average, people have been following the standard dietary advice.** For example, in the first graph, consumption of whole milk has gone way down. Conversely, low-fat milk consumption has gone up. How can obesity be getting worse? Are we wrong about whole milk being worse than skim milk for obesity?

Source: USDA, Economic Research Service, Food Availability (Per Capita) Data System.

This chart appears in "Trends in U.S. Per Capita Consumption of Dairy Products, 1970-2012" in the June 2014 issue of ERS's *Amber Waves* magazine, Accessed April 2, 2024 at: <https://www.ers.usda.gov/data-products/chart-gallery/gallery/chart-detail/?chartId=77627>

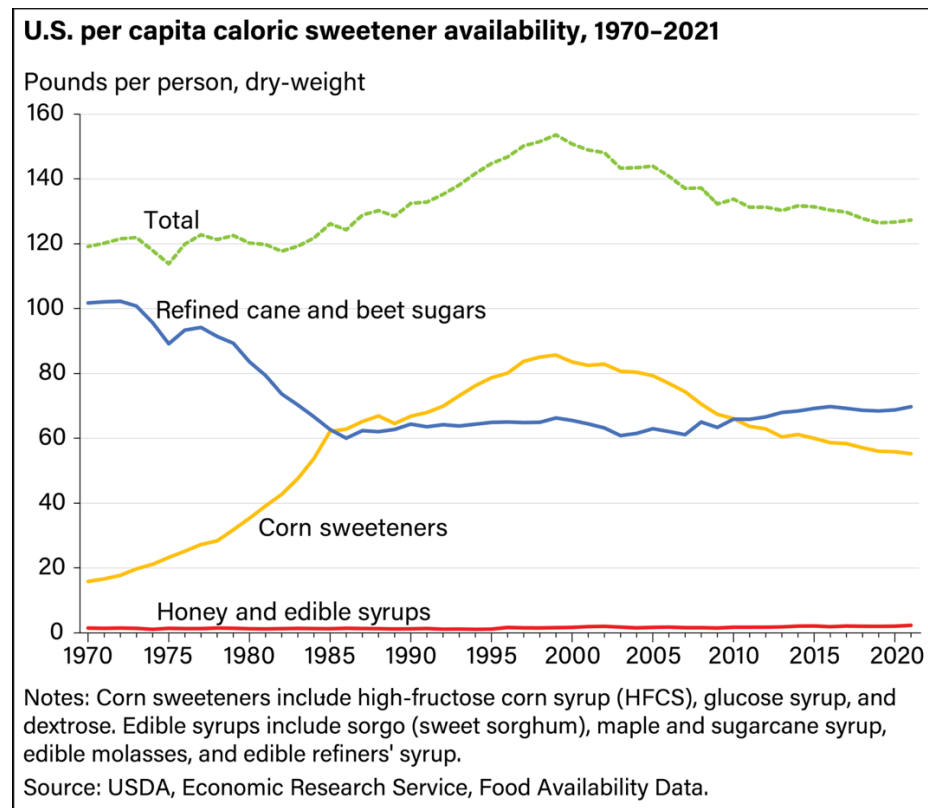
The next graph is interesting because it has a longer time scale going back to 1910. During the Great Depression, beef and pork consumption go down. After World War II, in an age of relative



prosperity, meat-eating shoots up. But there is no obesity epidemic then. In the 1970s, **health experts tell people to avoid red meat and people listen. Beef plummets. So beef consumption goes down as obesity starts going up.** With the advent of factory chicken farming, chicken production zooms up. Health advice to avoid red meat also propels chicken consumption.

U.S. Department of Agriculture, *U.S. per capita availability of beef, pork, chicken, and fish/shellfish, 1910-2021*, Graph, May 5th, 2023, (Economic Research Service), Accessed April 2, 2024 at: <https://www.ers.usda.gov/data-products/ag-and-food-statistics-charting-the-essentials/food-availability-and-consumption/>

I think the authorities recommended cutting back on red meat and whole milk because of the general idea that saturated animal fats cause heart disease. I'm not going to go over the strength of the evidence for that. What I want to focus on here is the consequences of the recommendations. **One big thing that happened with the "fat is bad" idea was the heavy marketing of "low-fat" foods as healthy, even if they were highly processed and/or highly caloric.** The most notorious example of this was Snackwells cookies. But there are still many foods that are Low-fat or Non-fat but full of sugar, like chocolate milk and many yogurts. As we can see, what did go up as the obesity epidemic took off was sugar consumption. Even "fruits and vegetables" can be heavy on sugars or carbohydrates. In the US, the main "vegetables" consumed are French fries and pizza sauce; the main "fruits" are apple juice and orange juice (according to other USDA graphs). Looking at these graphs does not prove that sugar is causing the obesity epidemic, but it does weaken the case against fat. It also argues against blaming the public for ignoring dietary advice.



U.S. Department of Agriculture, *U.S. per capita caloric sweetener availability, 1970-2021*, Graph, May 5th, 2023, (Economic Research Service), Accessed April 2, 2024 at: <https://www.ers.usda.gov/data-products/ag-and-food-statistics-charting-the-essentials/food-availability-and-consumption/>

Of course, there are other modifiable risk factors for obesity beyond sugar to consider: screen time, plastic food containers, endocrine disruptors, ultra-processed foods, antibiotics, gut flora, household chemicals, chronic stress, cars, social disintegration, diet soda and artificial sweeteners, crime, violence, fear, lack of sleep, junk food designed to be addictive, advertising, food deserts, junk food swamps, etc. This gets us to the notion of **multifactorial causality**. One health problem can have many causes. This can be hard for people to understand because it goes outside the Bio-Medical paradigm and the Doctrine of Specific Etiology. But the real world is complex.

Smoking and lung cancer is one of the most clear-cut cases of causality in epidemiology, but even there it's not all black and white. Not everyone who smokes gets cancer. Not everyone with lung cancer smoked. There is some combination of smoking and something else (unlucky genes?) that is necessary for contracting cancer. Nevertheless, the Hill criteria are met, notably

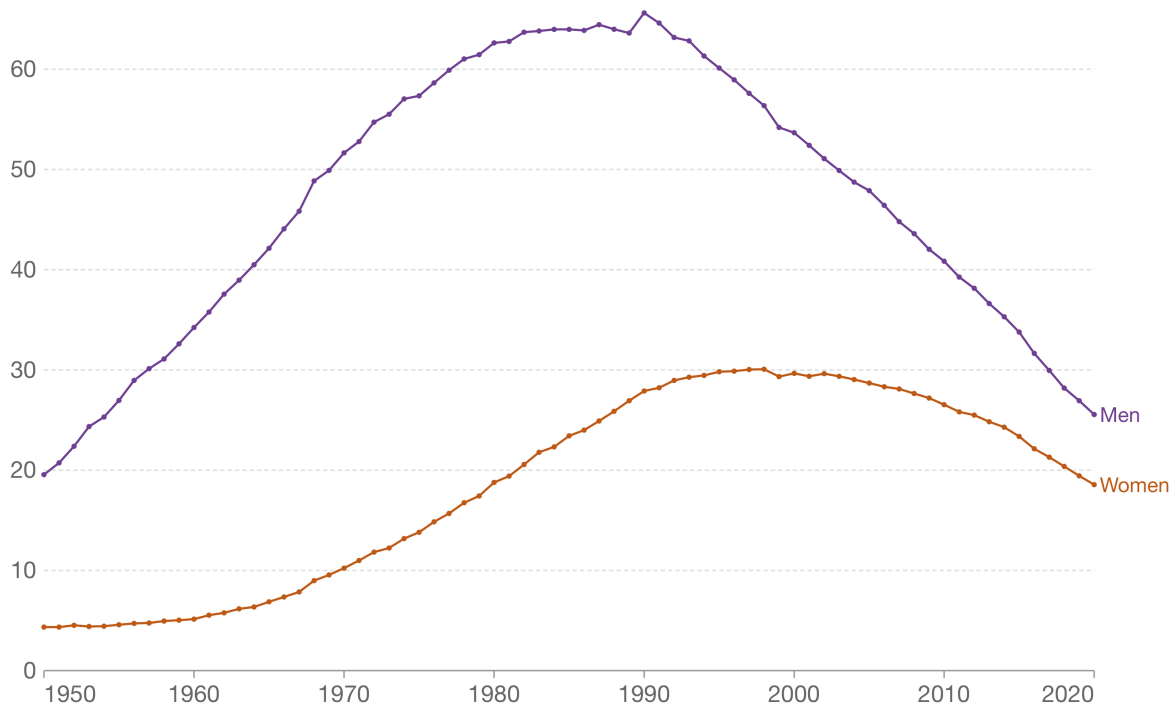
with an astounding increase in risk: smokers are 10 or 20 times more likely to get cancer than non-smokers. **Therefore, the public health implications are enormous, and that's what matters. The evidence back in the 1960s indicated that eliminating cigarettes would prevent millions of cases of deadly cancer.**

Since cancer takes a long time to develop, you would expect that cancer deaths would continue to increase for a few decades after the dangers of smoking became clear, but then would begin to decline after we started doing something about it. And that's what happened. Look at lung cancer deaths plummeting in the graph below! We do know stuff that helps people. It is possible to figure out if something in the environment is dangerous. And that knowledge can be turned into action that saves lives. **Don't believe the merchants of death when they try to trick you by saying we can't "prove" what "causes" health problems.**

Lung cancer death rates, United States, 1950 to 2020

Number of lung, bronchus and trachea cancer deaths per 100,000 people

Our World
in Data



Source: WHO Mortality Database (2022)

OurWorldInData.org/smoking • CC BY

Lung Cancer Death Rates, United States 1950-2020, Interactive Graph, 2015. Figure found at Roser M., Ritchie H. Cancer. Our World in Data website accessed April 2, 2024 at: <https://ourworldindata.org/cancer#citation>. Licensed under CC BY 4.0. Data published by World Health Organization Mortality Database.

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Chapter 6

Evidence-Based Public Health



“A great majority of the so-called educated people do not think logically and scientifically. Even the press, the classroom, the platform, and the pulpit in many instances do not give us objective and unbiased truths. To save man from the morass of propaganda, in my opinion, is one of the chief aims of education. Education must enable one to sift and weigh **evidence**, to discern

the true from the false, the real from the unreal, and the facts from the fiction.” -Dr. King, 1947

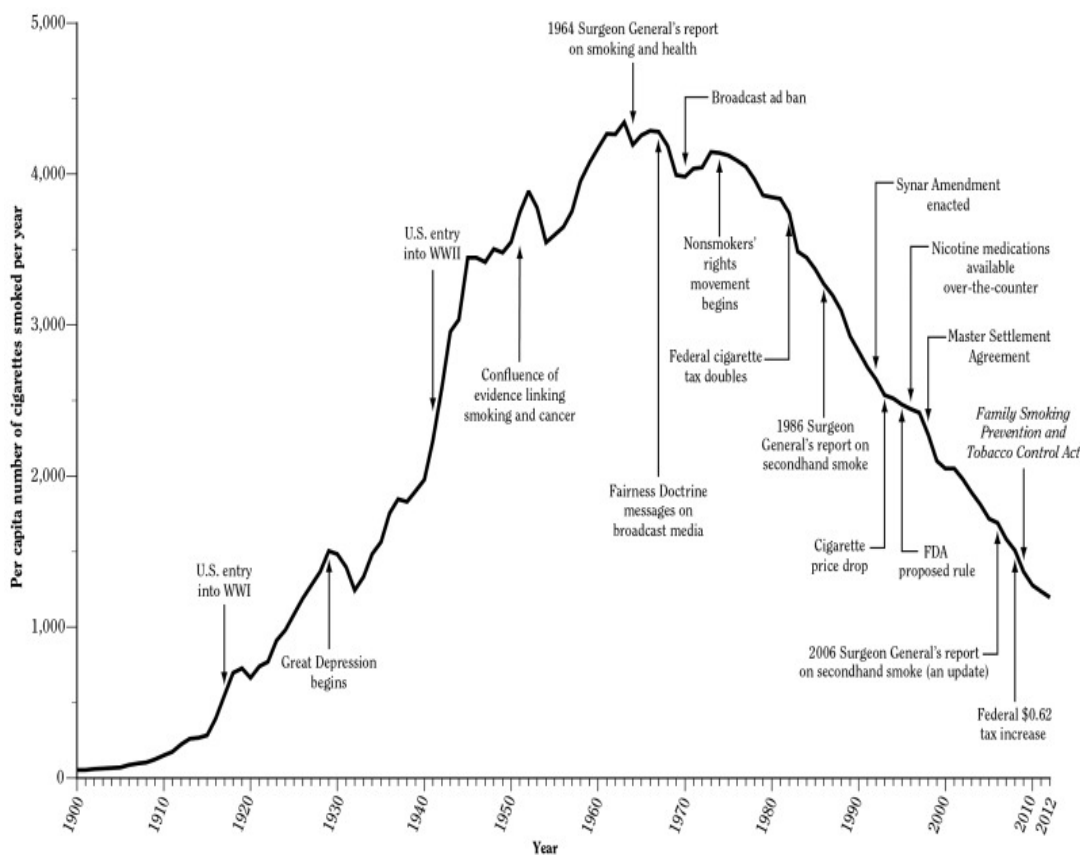
ABC Television, *Dr. King Open Hearing*, Photograph, June 5th 1957, Public Domain, via Wikimedia Commons, Accessed April 5, 2024 at https://commons.wikimedia.org/wiki/File:Dr._King_Open_Hearing_1957.jpg

Tobacco control as a model for community health action

In the Environmental Health chapter, we looked at how we know that cigarettes are dangerous. What causes cancer at a population level is a different question from why any given individual has cancer. For improving community health, causality is not about solving detective mysteries--it's about preventing death and disease. The findings from epidemiologic studies convinced people that smoking was dangerous, and so actions were taken in response to save lives. What worked for tobacco control?

Dr. Sommer (former dean of the Johns Hopkins School of Public Health) listed **the 5 “shuns”**:

1. Legislation
2. Regulation
3. Litigation
4. Taxation
5. Public education (Not individual health education. Community awareness raising.)



If we start by thinking of other health topics (e.g. obesity) as issues of environmental public health (instead of faulty genes or behavioral weakness or whatever) then it makes sense to **look at tobacco control as the model for what to do in community health**. As with the Swill

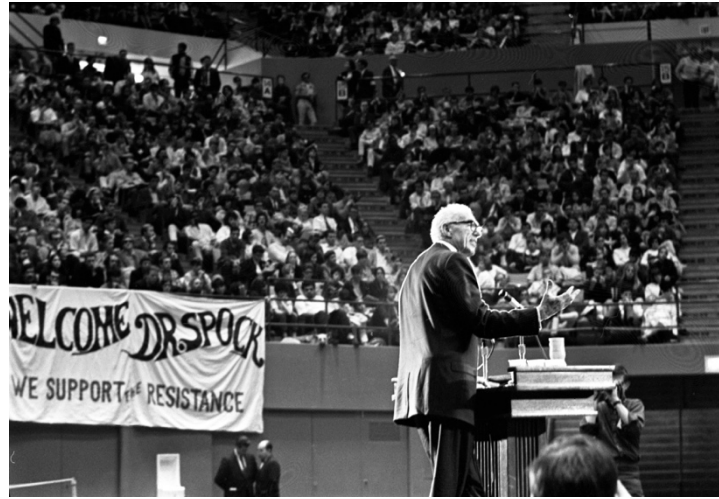
Milk story, if we can eliminate the environmental causes, then we can reduce morbidity and mortality even if we don't understand the underlying biology. Smoking is the number one preventable cause of death in the world. In the 21st century most of its victims will be in the "developing" world. Nicotine is an addictive drug that has been promoted by a very profitable international industry. Nevertheless, grass roots associations have managed to help implement social changes that have led to a decline in smoking. In the years to come, these efforts will prevent many premature deaths from cancer, heart disease, SIDS, etc. The turning point in cigarette-consumption in the U.S. occurred when anti-smoking public service advertisements began appearing on television. Local clean-indoor-air laws, increased taxes and other measures have also helped. Individual counseling by physicians has played a relatively small part in the story. "Leaders" like politicians often follow the public. Waiting for the President to wake up one day and fix a problem is not a great strategy.

Brave scientists needed to speak out and tell the truth in a way the public could understand it. But just getting the knowledge out there was not enough: cigarette smoking continued to increase after the evidence linking it to cancer was widely publicized. Activists needed to stick their necks out to start a movement to activate the 5 "shuns." Then, millions of ordinary people supported anti-smoking goals, creating a change in the culture. After that, laws were passed. Effective prevention is possible, but generally requires a concentrated population-based approach.

The tobacco control story illustrates how important it is for the community to be involved if we want to improve population health. Sometimes, people make an Either/Or out of Community and Evidence, saying that community involvement is good and evidence-based practice is bad. I feel strongly that this is a false dichotomy. I think it should be Both/And; **Community & Evidence**. People in the community want things to get better. For things to get better, you need to do things that work. To do things that work, you need to be able to "sift and weigh evidence." People want to believe that their ideas are good and that whatever they are doing is useful, but that doesn't make it so. An important example of that is the SIDS story.

The SIDS pandemic

The most famous pediatrician of the 20th Century was Dr. Benjamin Spock, who wrote the mega-best-selling parenting book “Baby and Child Care” in 1946. In the 1960s, he was an outspoken opponent of the Vietnam War and became a national political figure. **In 1956, he changed the advice on sleep positioning in his book.** To avoid the potential dangers of choking on vomitus, he told moms to put their babies to sleep on their tummies, abandoning the traditional practice of back-sleeping. As a result, the prevalence of prone sleeping increased dramatically in the U.S., eventually reaching about 70% in the 1980s. The practice then spread to Europe and as far as New Zealand. In Norway, for example, prone sleeping went from 7% in 1970 to 50% in 1985. Keep in mind, this remarkable increase in tummy-sleeping was because people followed the expert medical advice.



At the same time that prone sleeping was increasing, there was a global pandemic of SIDS (sudden infant death syndrome). By around 1970, epidemiological studies were pointing to prone sleeping as the likely cause of this epidemic. This prompted several countries to stop promoting tummy sleeping. In each country where they stopped pushing prone sleeping, there were dramatic decreases in SIDS. In 1994, the U.S. followed suit and launched its Back to Sleep campaign, which not only stopped promoting prone sleeping but also clearly recommended back sleeping. And US SIDS deaths decreased. Back to Sleep is a remarkable success story. But it hides a cautionary tale of an iatrogenic pandemic. Tens of thousands of SIDS deaths occurred around the world even after the epidemiologic evidence showed that prone sleeping was a risk factor. Dr. Spock and all the doctors, nurses and parents who followed his advice presumably meant well. I don't think they were trying kill thousands of healthy babies. **Imagine how you would feel if you had been telling multiple generations of families to put their babies on their tummies and then that turned out to be horrible advice.** I don't want you to feel like that.

There are many potential lessons from the SIDS story. Let's consider a few. On the positive side is how the epidemic got stopped. Once the evidence suggested that prone sleeping was the cause, the Dutch stopped recommending prone sleeping. They didn't recommend back-sleeping. They didn't campaign against tummy sleeping. They just stopped recommending it. **The burden of proof for stopping an apparently dangerous practice is not as**

high as for actively recommending something. Ceasing to push tummy sleeping was enough to make SIDS rates zoom down. Based on those real-world outcomes, other countries followed suit.

I don't think we need a randomized controlled trial (RCT) for sleep position and SIDS. No one ever did a randomized trial of cigarette smoking and lung cancer. And that's okay. I bring this up because one of the big lies used against evidence-based practice is that people like me are fanatics who refuse to accept the value of any program that has not been studied in multiple RCTs. RCTs for public health topics are often unimaginably impractical. But that does not mean we should be nihilistic about science and just give up and do whatever some famous dude says to do. Practicing in the absence of evidence is like driving blindfolded; you might get to your destination safely, but you are more likely to end up killing someone. You don't need an RCT to take important effective action. But you do still need to look at the overall weight of the best available evidence.

Good Intentions are Not Good Enough: Look it up!

True story: there once was a community where lots of people drowned every summer. The local health department decided to do something about it.

If you wanted to decrease drownings in your community, what would you do? Please stop here and write down your answer before going further. _____

I hope your answer was "Look it up!"

In the case of the health department, they decided to provide free swimming lessons. They assumed, quite reasonably, that people drown because they do not know how to swim. Drownings did not go down; they went up. **The only way to know if something works is to measure outcomes.** (Note: "outcome" is distinguished from "output" or "process" or "leading measure" by being the relevant result you're trying to achieve to make things better for someone. Counting how many people got swimming lessons is not a relevant outcome for drowning prevention. The outcome is drownings.)

To get an idea why the swim lessons program maybe didn't work, you can look at the graphic above. Official recommendations for drowning prevention do include "Learn to swim," but they make a point of specifying "Learn to swim *well*" and the photo is of a baby. Although it's hard to know exactly what is happening in this story, the thinking is that when you teach a bit of basic swimming to teens or adults, then they move from just sticking their feet in the water to going in all the way, which dramatically increases danger, especially if they are inexperienced swimmers unprepared for currents or other problems. **As the poet Alexander Pope said, "a little learning is a dangerous thing."**

You can't look up everything on every topic. Nobody can. If you haven't looked things up on some topic, then accept your limitations and just admit you don't know. That's okay. If you can't swim, stay out of the water. What's bad is everybody jumping in the ocean when they don't know how to swim. **But in your area that you are passionate about, you can go deep. Don't just dip your toe in the water. Dive in. Be the expert.** If you have critically read a few key articles on your problem of interest, you'll know more about effective solutions than most people.



Illustration by Andy Aligne for this book, with permission. Simplification of concepts from: Frieden, Thomas. 2010. "A Framework for Public Health Action: The Health Impact Pyramid" *American Journal of Public Health* 100, no. 4: 590-595.)

Easy EBP

You don't have to be a statistician to assess the evidence. The main skill is the habit of asking "How do we know this works to help people?" Beyond that, there are some tools that you can use to quickly give you an idea if something is likely to be useful for improving community health.

The CDC's Health Impact Pyramid can give you some prior probability clues. Things at the top of the pyramid (individual-level counseling and education) are likely to have low bang for the buck. Unfortunately, these are the things we tend to think of first, like swim lessons for teens. Things at the bottom of the pyramid have the biggest bang for the buck

because they get at root causes. If you are working three jobs and will get fired for taking time off, you probably can't go to mommy-and-me swim lessons with your baby. So decreasing wealth inequality would do something about that, but that's not an easy program to implement. **The next level up in the Pyramid therefore tends to be a sweet spot for community health: changing the context to make default decisions healthy.** If you encourage fences around home pools, or have lifeguards who enforce rules against drinking alcohol on beaches, you will probably see a decrease in drownings. There are many examples of successful community health interventions like this ranging from water fluoridation to childproof caps on bottles of pills and household chemicals. What they often have in common is **passive prevention**, as opposed to active prevention where individuals have to make an effort over and over again to avoid the danger (such as fastening a seat belt). In the chapter on Behavior Change, I talk about this approach as lowering barriers to healthy behaviors and raising barriers to unhealthy behaviors.

The middle level in the pyramid is for Long-lasting preventive interventions, like vaccines. That's excellent stuff too and could use a lot more attention, but it's just not the main focus of this guide. The next level up is Clinical intervention, like medical or surgical treatment for after people are already sick. This is where we spend most of our healthcare money and time in the US now, and by many measures this is not a cost-effective way to increase population health.

Heuristics* like the Pyramid can help you figure out quickly broad categories of interventions that are more or less likely to be impactful. For more specific information, there are numerous resources that collect and assess evidence-based practices. The most famous of these is Cochrane. People tend to think of it as being only for medical trials, but it covers public health topics as well. The CDC's Guide to Community Preventive Services (commonly called The Community Guide) is more focused on public health. The US Preventive Services Task Force is about clinical prevention, but this has some overlap with public health, and the methodology is interesting if you want to become an evidence nerd. There are other more topic-specific collections from the government that are useful depending on your area of interest. There are also assorted independent clearinghouses for evidence-based programs; these sites sometimes have hidden agendas and I would be more wary of those. You can always just go to PubMed or Google Scholar and find a meta-analysis. This is often a bad idea however, because there's a fair chance what you'll get is a shmeta-analysis, i.e. many small bad studies smushed together into one large bad study. If you are going to look at a review article, try to find an evidence-based literature synthesis that describes the strengths and weaknesses of the key papers, and then go read at least one of those papers.

You can radically reduce the number of papers you need to look at by limiting your reading to articles that show the intervention decreases the number of people with a bad

objective outcome. Did fewer people have cancer, SIDS, car crashes, obesity, suicide attempts, or whatever? Otherwise, so what? Changes in some lab test or a subjective questionnaire are not relevant unless they are established validated intermediate outcomes that predict the real outcome. Fancy statistics are a red flag. Even p-values are often hacked and meaningless. And so on. Even though there are zillions of papers out there about SIDS, for example, it turns out that most of them do not tell you anything interesting about what caused the pandemic or how it was stopped. The ones with simple graphs of SIDS zooming up and then zooming down tell the whole story.

If you start out with “*How do we know this works to help people?*” and stick to that, then sifting and weighing the evidence will be much easier.

*Do you know what the word “heuristic” means? If yes, good for you. If not, great for you, because you can look it up and learn something new. How exciting!

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- Evidence Based Policy Resource Card



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- Pyramid illustration by Andy Aligne for this book, with permission.

Chapter 7

Project Planning

"The best way to have a good idea is to have a lot of ideas."

-Linus Pauling, Winner of two Nobel Prizes

"If you have built castles in the air, your work need not be lost; that is where they should be. Now put foundations under them."

-Henry David Thoreau



Becker, Murray, Associated Press, Hindenburg Disaster, Photograph, May 1937, Public Domain, via Wikimedia Commons, Accessed April 5, 2024 at <https://commons.wikimedia.org/w/index.php?curid=27765273>

Don't reinvent the Hindenburg.

If this is your first community project, the point should be for you to learn useful skills, not for you to save all the people in town. You should feel autonomous, but not alone. Ideally you will have several mentors. A good mentor is someone you trust and respect, who is available and supportive but both frank and challenging. When you find a mentor, let her or him help you: **your mentor should be stretching you, not just patting you on the back.**

When looking for inspiration about what project to embark upon, take your time to read broadly and look at the whole picture. In general, the hard part won't be finding a problem. Nevertheless, if you feel stuck at any point in the process of project planning, brainstorming with others can be very helpful. **The main rule of brainstorming is that nobody criticizes anybody else's ideas.** Period! No exceptions! Sometimes the zaniest ideas turn out to be the best ones. Write all of them down because all ideas are okay during brainstorming.

After brainstorming, you can sift through all the rubble for a gold nugget and prioritize that. Once you have developed some preliminary broad idea, do some research to narrow it down. When you have a focused idea of what to do, but before you start doing anything is when you really need to get some outside input. It is critically important that you:

DON'T REINVENT THE WHEEL!
DON'T REPEAT PROVEN MISTAKES!

Learn what others did, decide what worked, and identify the barriers you may face. Read the literature. Talk to people locally, including CBO clients and staff members with existing connections to your program. When you have a clear vision, you should develop a one-page mini proposal for your project. Writing a proposal will help with organizing your ideas, communicating your plan, applying for funding, etc. Even after all that, you might find that you need to change your plan. Maybe something awful happens like your CBO steals your funding. Whatever. Community work is messy. Stay true to your big goal and correct course.

The community is the expert of its experience; you're the expert of what you know.

"Some people say, "Give the customers what they want." But that's not my approach. Our job is to figure out what they're going to want before they do. I think Henry Ford once said, "If I'd ask customers what they wanted, they would have told me, 'A faster horse!'" People don't know what they want until you show it to them."

-Steve Jobs

People can't tell you about things they can't imagine.



Matthew Yohe, CC BY-SA 3.0
<<https://creativecommons.org/licenses/by-sa/3.0/>>, via
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https://commons.wikimedia.org/wiki/File:Steve_Jobs_Headshot_2010-CROP.jpg

If you know about something that could help people and that they would really want if they knew about it, there is nothing wrong with offering it to them. Offering a solution is not the same as forcing it on people. In fact, it's more like the opposite, because **by withholding a solution from people, you're often forcing them to do without it.**

Don't get trapped in a false either/or of "listening to the community" or "doing evidence-based community health" ... Use the **magic of &**. You should be ready to propose evidence-based solutions AND to listen to what the community wants. Forcing something that nobody wants is a bad project, but so is wasting time on a popular program that doesn't work. Before or during the pilot testing phase of your project, you should be establishing the feasibility and acceptability of your intervention. Always strive for the win/win. This should happen naturally if you are engaged in an authentic partnership and using the tools of honest cross-cultural communication.

There are many organizations, consultants, websites, and other resources out there to help you with how to connect with partners and plan a project. Nowadays, some funders even require participation in workshops on including community voice. So, I feel that I don't need to elaborate on that here. Unfortunately, what I have seen repeatedly is big, happy, enthusiastic collective efforts to do stuff that has no evidence behind it. The collaborative action is there. Money is being spent. Things are being done all the time. And yet we are making too little progress with too many problems. I am hoping that readers of this handbook can **help include the perspective that we already know a lot about what works to help people** among the cooperative mix of voices in community endeavors.

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Chapter 8

Simple Evaluation



Illikefood at English Wikipedia, Public domain, via Wikimedia Commons. Pudding photo. Accessed on March 14, 2024 at https://commons.wikimedia.org/wiki/File:Pudding_With_Raspberries_and_Whipped_Cream.jpg

The proof of the pudding is in the tasting.
—Old saying

Why Do Evaluation?

We have finite resources. If we waste them on programs that are predictably useless instead of helping people, then that's wrong. Unfortunately, as we've seen with numerous examples, that's what keeps happening. Fortunately, as we saw with SIDS, or swill milk, or smoking, it's possible to figure out what's working without fancy statistics. You might wonder why you need to evaluate your project if you're following evidence-based practice. **If you maintain "fidelity" to an established, proven practice, you should be okay. The problem is that reality is often different from theory. If there's no follow-up to see if people actually got better, something is missing.** The way to know if your program is working is to track outcomes.

With community projects, this follow-up can seem difficult because your unit of analysis is a neighborhood or a school district, and your timeframe might be measured in years. There are lessons we can learn from successful public health programs to design simple but useful evaluation for your project.

If You Evaluate, Dare to do it Well!

Unfortunately, a lot of the evidence for community projects is pretty weak. D.A.R.E. (Drug Abuse Resistance Education) is one of the biggest most expensive community health programs ever. At one point their website boldly stated: *"D.A.R.E. Works and We Can Prove It!"* Backing this up were the following findings:

"Teachers surveyed gave an over-all rating of the D.A.R.E. program in the good to excellent range of 97%. D.A.R.E. effectively teaches children to say no to drugs and violence according to 92.8% of parents surveyed. 86% of principals surveyed believe students will be less likely to use substances after the D.A.R.E. program."

What do you think about this evaluation? It's quantitative: there are numbers and they even have three significant figures. **That is very scientific! But it's just documenting that people seem to like it. So even if the results are quantitative, they're still subjective,** i.e. they're measuring opinions or beliefs. The problem is that there is no relevant outcome. If D.A.R.E. is meant to keep kids off drugs, then a strong evaluation would measure the impact on drug use. Basically, this would involve counting of the kids on and off drugs, with and without D.A.R.E.

SIMPLE EVALUATION

People had a good result?
(*relevant objective outcome*)

Yes

No

People got
something done?
Yes
No

Possible Benefit	No Benefit
Improved On Their Own	Failed To Improve

Illustration by Andy Aligne, with permission. Based on design by John Wax.

Fortunately, this is pretty simple. **You don't need statistics! You just need to be able to understand a 2x2 table.**

All you really need is a primary relevant outcome that you can define as Yes/No and then some kind of comparison group of people who didn't get the intervention. Since you're probably not doing an RCT, the comparison can be before/after or can look at the "secular trend," which is fancy talk for what's going on in the general population.

One of the biggest problems for community work is using impractical evaluation tools that are too complex; e.g. 76-item written questionnaires for children to fill out. If you have to do a survey, I would strongly recommend keeping it short, and in simple language (you can check grade level right in Microsoft Word), as you should do with any written handout. If you're doing a serious survey for research purposes, there are many additional requirements to consider. **But for the sake of program evaluation, I would first stop and ask yourself if you even need a survey.** After all, the survey in the D.A.R.E. example didn't really help at all to evaluate the effectiveness of the program.

What kind of evaluation is needed depends on the stakeholders involved. A "warm-body count" as it is derisively called, i.e. a tally of the clients served, is often all that's required by funders. The problem with just counting clients is that everybody is biased towards thinking that whatever service they are providing is useful, but sometimes it isn't. **All those police officers volunteering their time in D.A.R.E. to talk to school kids presumably believed they were helping by talking about how children should avoid drugs. If you believe that, then it makes sense to count how many millions of children have been through D.A.R.E. and conclude that you've done a lot of good.** The problem is that when researchers rigorously evaluated D.A.R.E., they found it didn't help. (Perry CL)

Tracking results is basic. This is not about how to do research in a multi-million-dollar NIH-funded project. If you do need a formal evaluation, then you should get help as needed from experts in statistics and research design. Generally, in small community projects this is not required and is not the issue of what's wrong with most evaluations. **If you just measure one relevant outcome and have a comparison group, you will be doing a better job than many community programs, including gigantic ones like D.A.R.E.**

Taste the Intermediate Found Data

People often say “the Proof is in the Pudding.” Actually, the saying goes: “*The proof of the pudding is in the **tasting***” – That is to say results are what matter. The value of your program is not that it exists; the value is the benefit to the user/client/patient/neighborhood/population. Evaluation is how you decide if your program does have value. How do you evaluate a pudding? You don't X-ray it or analyze the chemicals or stare at it; you taste it.

So, you need to measure results. The problem for many community projects is that the primary results may take years to see or may be very rare. For example, if you're doing an obesity-prevention project, you don't want to wait 50 years to see if people get heart attacks! Instead, you might measure an **intermediate outcome** – i.e. something that is known to predict your final outcome of interest but is easier and faster to detect; let's say physical fitness.

If you are doing your program with a school or some agency that already measures fitness routinely, then you don't even need to do anything to measure that outcome. You can just collect reports that are already there. This is called using *found data (also known as administrative data)*. **There are numerous advantages of found data: it is usually cheap, easy, fast, already relevant to somebody, quantitative, longitudinal, and available for a “control group”.** So, two big tips for making evaluation easier and better: look for intermediate outcomes and for found data.

Ethics

If you are going to do research, you should make sure you fill out the appropriate paperwork with your local Institutional Review Board. More importantly, you should obey the principles of bioethics in everything you do, including community projects that do not involve research.

The four fundamental principles of bioethics are: autonomy, beneficence, nonmaleficence and justice. **Autonomy** is the right of a mentally competent person to make his or her own decisions with informed consent. The principle of **beneficence** is to make conditions better for others. Very similar to beneficence, is the principle of **nonmaleficence**, which comes from the most basic maxim in medical ethics, *primum non nocere*, “above all, do no harm.” These two principles are often grouped together. You must create a positive balance of good over harm because almost all treatments have some potential adverse side effects. The fourth ethical principle is **justice**, which deals with social cooperation. A recent related term is “equity.” Sometimes, the principles are in conflict with each other. In community work, a particular concern is engagement/voice/participation/diversity/inclusion. This is about balancing autonomy and justice. This should be baked into your project if you are working in authentic partnership with a community-based organization that directly involves community members. And you still need beneficence and non-maleficence.

Doing research is not the point of this field guide. What we're focused on here is the application of what's already known as opposed to the generation of new knowledge. However, **sometimes by implementing a program in the real world, we learn lessons that are worth sharing, and then it makes sense to publish it.** This is even a growing area of research called

Dissemination and Implementation research or T4 Translational research, that is all about how to scale things up in the real world. So, doing what works and research can be a Magic of &.

Historically, there have been infamous breakdowns of ethical behavior in medical research like the Nazi doctors, the Tuskegee Syphilis Study, the Rochester Plutonium Experiment, etc. These types of atrocious behavior aren't generally a problem with people like you who volunteer in community health, so I am not going to discuss them further here. Another massive, ongoing problem is that much of health research is just bad science. But that's also beyond the scope of this course.

The big ethical failing I do see in community programs is that well-meaning people keep doing things that are already known to be useless or harmful. At the very least this is squandering vital resources by diverting limited funds and person-power to time-wasting silliness. At worst, this could be killing kids. So, please don't reinvent the Hindenburg! Please spend ten minutes online looking stuff up before you start something to see if it's already proven to be a problem. **Please!!! Doing the right thing means doing things right.**

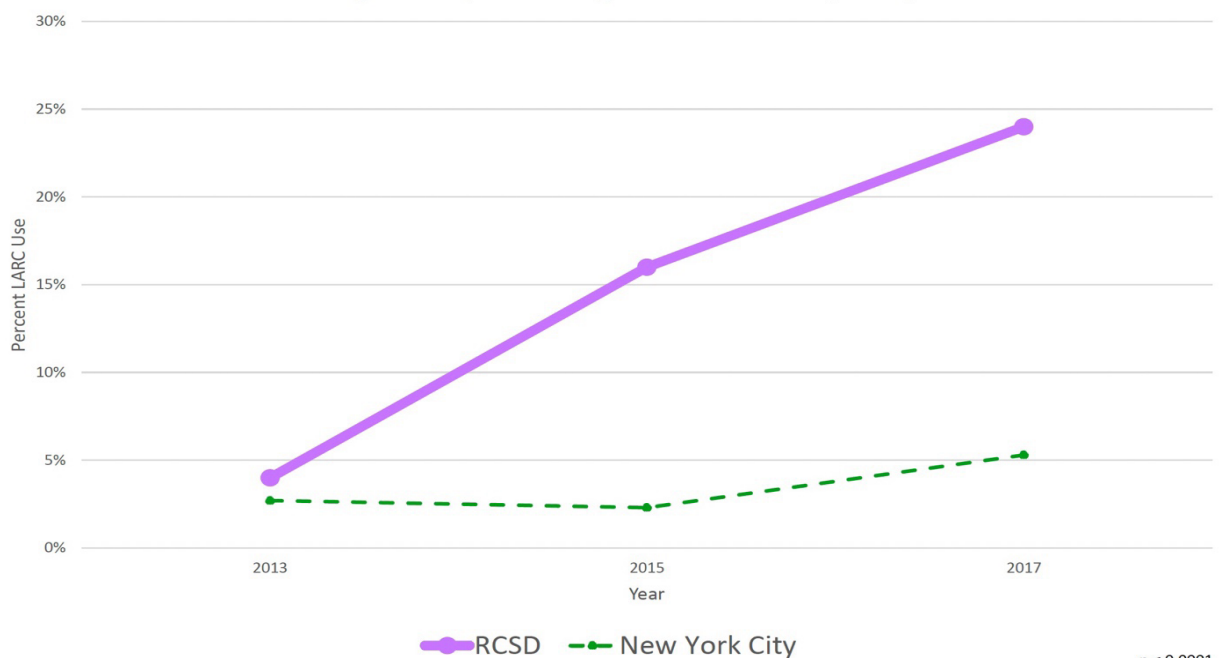
Case Study: The LARC Initiative

The LARC (long-acting reversible contraception) Initiative grew out of project called Evidence Based Contraception, which was started by two residents named Anne Huber and Hilary Yehling. The background was that there were unintended teen pregnancies occurring because teens and young women did not have access to the most effective types of birth control. The project involved educating and doctors and community adults who work with teens about LARC so that people could make informed choices based on accurate information about safety, effectiveness and access. In studies where women seeking contraception are offered all methods for free with structured fact-based counseling, about 70% choose LARC. Patients should never be coerced into using LARC or any other method, but when LARC usage is around zero, that indicates that people are being denied access.

Multiple approaches were used to see whether the initiative had any impact. Using a quasi-experimental design (before-after with a control group), we looked at found data from the CDC's YRBS (Youth Risk Behavior Surveillance System) and compared LARC usage locally vs. the state, the nation and NY City. LARC use increased locally (in Rochester) much more than in these other locations. In addition to looking at these public health data, we collected testimonials to verify that people were happy with the way we were presenting information. While watching for problems, we also documented positive ripple effects. None of this is a randomized trial. Some of it is not even research. But overall, it amounts to a convincing picture that we moved the needle at a community level on a public health priority.

Rochester vs. New York City

LARC Use among Sexually Active High School Females, YRBS, 2013-2017



"I shared the information with my 17-year-old daughter. LARC has given her the freedom to protect herself and make her own choices. Reproductive health planning can be difficult for parents but having access to a safe and reliable option for my own daughters has eased the process."

"My favorite part of the presentation was the food and great presenters. Very informative!"

"They went above and beyond to answer my questions. This is a must-see presentation for anyone working in reproductive health."

"Nice balance of education and research-based material that is accessible and easy to understand for individuals of all backgrounds."

Institutionalization of contraceptive implant insertion training for all pediatrics residents at the University of Rochester.

Helped interested practices become a Family Planning Benefit Program enrollment site. This is a New York State insurance program that covers reproductive health services.

Ripple Effects of the LARC Initiative

Facilitated connections for practicing providers interested in becoming trained in LARC insertion to required trainings.

Launch of Stay True to You, a collective impact media campaign to empower young women to make informed reproductive health decisions (Figure 6).

LARC Initiative Graphs: Jessica Van Scott, with permission.

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- 2x2 evaluation table illustration by Andy Aligne, with permission. Based on design by John Wax.
- LARC Initiative Graphs: Jessica Van Scott, with permission.

Chapter 9

Communicating Your Message

- ❖ People often feel that they're obliged to use PowerPoint slides like this one **with just words on them** and then to *read every line* as if the whole audience *were* blind or illiterate.
 - As far as I know, this is not actually a rule for any venue.
- ❖ You *don't have to* do a 'pretty bad' presentation just because that's what others are doing.
 - ❖ The original point of the slide show, was to show *pictures/graphs/charts*, etc. as visual aids.
- ❖ All speaking EXPERTS **agree that PowerPoints with** just words make for **pretty BAD talks**.
- ❖ If you **insist** on an all-word slide presentation, then at least have legible slides – a good rule of thumb is no more than 8 lines of text per slide.
 - ❖ And don't **very fonts** for no reason or make spelling errors
- ❖ Or B R E A K L I N E S with bullets for no reason. Or bury the most important point in a lot of extraneous verbiage. Because then the spaceship will

Slide by Andy Aligne, with permission

*"There are two types of speakers:
those who get nervous and those who are liars."*

- Mark Twain

Connecting With Your Audience

Whatever the type of community project you do, it will probably involve some kind of public speaking, whether it's to encourage community members to partner with you, or funders to fund you, etc. Even for an academic audience, it's not just what you say that matters, it's also the way that you say it. You should **avoid technical language** or jargon terms that your audience might not understand.

By using **specific examples of people affected** by your issue, you are putting a face to the issue being discussed. When appropriate, use personal anecdotes to illustrate examples of the facts that you are talking about. People are going to understand and be persuaded more by real life stories than by statistics. When presenting statistics, unless it is absolutely necessary to use extreme precision, try to round things off and use normal day-to-day terms, such as "almost half" instead of "49.7%".

Since attention comes in waves, it is important to repeat your key points so that people retain the important information. **Try to begin your presentation with a question, mystery, or attention-grabbing hook**, which will help people to listen to the rest of what you are about to say. Your introduction should motivate them to listen to you, and your conclusion should offer them a final, insightful point. This should be your "take home message."

Persuading Your Audience

Start with what the audience knows, but **don't overdo it with background**. This is a common rookie mistake. It leaves the audience bored or frustrated before you even get to your point. If you finish on time, you can answer questions to clarify details that people didn't get.

If you're worried about taking questions, don't be. **Any question can be answered with some variation of "I don't know"** like "That's beyond the scope of this talk" or "I'll get back to you" or "That's very interesting but would take too long to answer right now." Pick some "I don't know" variation that you like and practice using it. Never lie. Never quote stats that you do not know; you can say "let me get back to you with those numbers, but what I can tell you now is..."

There are three basic components to persuasive argument, going back to Aristotle. These are Ethos, Pathos and Logos. A good talk will incorporate the three elements in that order.

Ethos refers to one's credibility with the audience. An easy way to get some ethos is an introduction by someone they already know. So, **it's useful to supply your hosts with a brief bio that highlights what you want the audience to know about you**. A white coat or a suit gives instant credibility, but it may be completely inappropriate in some community settings. That doesn't mean however that you can show up in shorts and a T-shirt for a project meeting. If you're doing a presentation, you're giving a performance; so wear the right costume.

At lots of talks, I hear the speaker start by apologizing about how bad this talk will be. People often do this out of humility or to get sympathy, but it just starts things off badly for the

audience by setting low expectations. This is an easy item under your control. **Don't start by apologizing.**



Photo of Aristotle sculpture: Accessed April 3, 2024 at https://commons.wikimedia.org/wiki/File:Aristotle_Altemps_Inv8575.jpg.
Sculpture after Lysippos, Public domain, via Wikimedia Commons

Pathos refers to the emotional component of your argument. Often, this is the most important part, as people will make decisions based on emotional factors, even if they rationalize them later using logical or ethical grounds. Therefore, to make an emotional connection with your audience, it is okay to use things like pictures of sick children, if they are authentic. Stories about people are much more engaging than statistics. If you look at the master professional communicators in the world, do they use word-only PowerPoint? No! Politicians and businesspeople all use images and stories to communicate. We can do that too. **Finding some pictures for telling a true story about the type of people that you're trying to help is something that most of us can do for our projects.**

Logos is the logical, factual, objective component of your argument. Although you may have worked very hard to present arguments based on evidence, the Logos component will usually not persuade your audience all by itself. Nevertheless, you must make sure that you are not taking it lightly and that you can back up whatever facts you are citing. If you are uncovered as being dishonest or sloppy, you will lose trustworthiness and future credibility. (This was at least true before the Post-Truth Era and will presumably happen again someday.) While most public speaking tips focus on the surface, the substance is what ultimately matters. So, know your material. If you care about your topic, you will be okay even if the projector breaks or the lights go out, or whatever. If you've prepared a talk on any topic, you probably know more about it than 90% of the audience. You are the expert. It's better to make one point clearly than to cram tons of information into your talk. **If you had to fit your message on a bumper sticker, what would it be?** Make sure people receive that message.

Practical Tips for Successful Presentations

If using a microphone during your presentation, do not hide your face behind it. Try looking towards the back row of the audience and moving your head; this looks like you are trying to make eye contact with everyone. With certain types of formal presentations, if there is no other way you can do it, you can have everything written out and simply read it. But I think you can do better. As much as possible, try to be conversational, **as if you were explaining something that you are passionate about to a few acquaintances.**

Depending on what your natural style of speaking is and what kind of talk you are presenting, you may need to speak more quickly, more slowly, more loudly, or more softly than whatever is normal for you. You may also need to use more gestures, or fewer gestures. It is

very difficult to give a set of strict rules. Therefore, you should try to figure out what works best for you by conducting some type of **rehearsal**. You can do this by simply practicing your talk alone with a voice recorder and listening to yourself. Other ideas include videotaping yourself, rehearsing in front of a mirror or gathering friends together to critique your presentation

To prepare for any type of presentation, it is helpful to know who your audience is. Remember that no matter what you do, if you are speaking to a large audience, some of them may not be interested in what you have to say. They may be tired. This is not your fault. Think of it as if **you are giving a present to a large group of people, and some people like it and some people don't**. (Get it? "Presenting.")

- Remember to have fun. This is your chance to get your important message out there. Be on fire, be passionate. If you don't care, why should they?
- Don't finish late. The best talk in the world is a loser if it makes everyone in the audience late. If you lose track of time on your own, then figure out a way to compensate: get a great big watch or a timer or ask someone in the audience to tell you when you have ten minutes left.
- You should know how long your talk will take because you should practice it first.
- Do practice. It's very easy to tell the difference between a rehearsed and an unrehearsed talk. Even just doing one run-through will make a big difference. I find it very hard to tell how a talk will flow unless I rehearse it.
- This does not mean you should memorize your talk as a professional actor would. You can use notes, or look at slides, or a whiteboard or flip chart or **whatever works for you**.
- Anticipate possible questions and formulate your answers ahead of time. Consider having one to three back-up slides that would help you answer these expected questions.
- Problems with A/V equipment can usually be dealt with by arriving early and checking that everything works. If things don't work, it's nice to have a printout of your slides/talk: it's hard for a piece of paper to have a malfunction. Eliminate this source of worry.

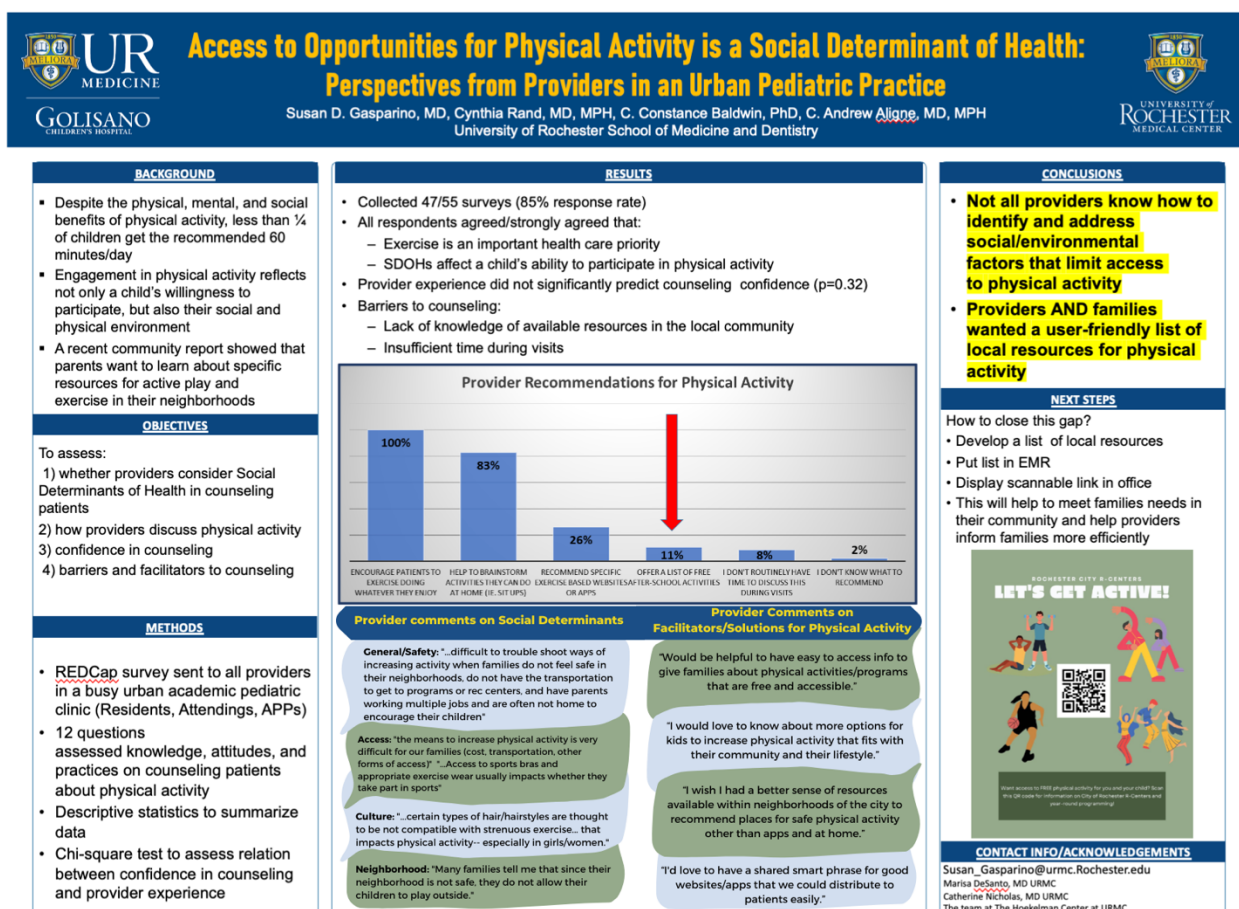
Fear of Public Speaking

Some people are very afraid of public speaking. If you are one of them, do not worry. There are others like you who have learned how to be effective public speakers. Even professional performers get butterflies in their stomachs before going on stage. Before you turn to medication, there are many books and seminars that you can utilize to improve your public speaking skills. Also, there is an international not-for-profit group called Toastmasters. **Public speaking, like anything, becomes easier as you do more of it. Start out small in a way that is comfortable for you** and then proceed from there.

I think it's a big mistake to try to learn public speaking by looking at videos of the great masters like Martin Luther King Jr. or TED talks or famous actors. That's not a realistic goal for most of us and it just creates extra stress to think that's what you're shooting for. It's much more reasonable to try for "a pretty good presentation." Most of us have the experience of attending lots of lousy presentations – **so if you can achieve "pretty good" status, you'll be way better than average! And the good news is that getting to "pretty good" is actually not that hard!**

Poster Presentations

When delivering a poster presentation, be prepared to “walk through” your poster and explain the various elements on it. Your poster should have clear, distinct sections. Use large, clean fonts so that it is easily readable from a distance. The text should not be smaller than 24 points. The only exception to this is when you type acknowledgements, references, and minor items. Posters, like slides, are an audio-visual medium. Try to think about the creative use of clear and relevant pictures, diagrams, etc. A poster with nothing but words in tiny fonts will not be very effective. **One clear graphic may do the job much better than an entire poster full of words.** The poster below is an example of the newer “better poster” style and it worked quite well at a large international meeting.



Poster by Susan Gasparino, with permission.

Details about slides

The point of using slides or other presentation aids is that they are audio-visual. **A picture is worth a thousand words.** It is okay to have fun with your presentation, to use colors, animation, interesting formats, cartoons, diagrams, or interesting drawings. Part of communicating effectively is to entertain, and if you are attracting people's attention and helping them to remember what you are saying by using visual aids, then that makes your presentation more effective. The reason that so many presentations include nothing on the

slides except the word-for-word text of the talk is that this is a very useful crutch for the speaker, who does not have to worry about forgetting what he or she is supposed to say. However, this is not the best way of communicating information to an audience. If it were, then that is what ads would look like. While you do not want to include information on your slides that you are not going to talk about, it is not necessary to have every single word of what you are about to say printed out on the slides or in your handout. If you can remember what you want to say by just using bullets on the slide, then that is a better way to communicate, because it will make the slides much easier to read and allow room for useful illustrations. However, be careful not to go overboard with audiovisual gimmicks. You do not want people to remember your animations and forget the message you want to deliver.

- One slide per minute during your talk is a good guideline.
- As is one hour of prep time per slide.
- Each image should visualize one main idea.
- Make sure that any diagrams utilized are easily visible.
- Bullets are great!

Wasn't that easier to read than the long paragraph above?

How to speak to the Media

If you are lucky or good or very naughty, you will have the opportunity to talk about your project on TV, radio, etc. The reporters might talk to you for twenty minutes, but then cut that to a ten second soundbite. So, **focus on your soundbite**.

Reporters know about reporting, but **you should assume that they don't know anything about your topic**, so it's your responsibility to make your point clearly and accurately. They generally want to help you with this, but they work under tremendous deadline pressure and don't necessarily share your priorities. Do not feel obligated to answer any particular question or even to talk to them at all if you don't want to. Stick to what you're qualified to answer. You can say something like "That's interesting, and it reminds me that ..." Do not ever say anything you would not want to see in tomorrow's news. On TV, reporters offer to talk "off the record." In real life, you're better off assuming that that's not a thing.

Appropriate body language during an interview is extremely important. When you are being interviewed, maintain constant eye contact with your reporter or look directly at the camera. You should also **smile, even if it is a serious subject**. When on camera, smiling appears neutral to your audience. Be animated, using your head and facial expressions, but keep your hands still. Maintain posture, sit up straight and lean forward towards the reporter. Avoid wearing anything too shiny or jangly.

As far as social media are concerned, I have a brief note on that in the next chapter.

Notes on Written Communication

At some point, you may want to formally write up something about your project for a publication such as a newspaper, a medical journal or a magazine. Since the various formats of publication require very different writing styles, we will not go into detail here. However, note

that if you have already prepared a slide show or a poster on your topic, you are well on your way to having a good starting outline for your written work. So, when you are cutting down all of your notes and materials on your topic to fit onto a poster or a few slides, remember to **save the initial longer versions and all of your notes and references**; they may come in handy.

A note on remote presentations

- Avoid backlighting in your real space. Make your face visible.
- Avoid unprofessional backgrounds.
- Rehearse with the platform to learn its features (whiteboard, etc.)
- Look into the camera.
- Get someone else to facilitate the chat area comments.

Conclusion

Whatever your project is, you are the expert of that and the people in the community are the experts of their experiences. **Craft the message you want to share** by combining those perspectives. Then frame it as Ethos, Pathos, Logos. By following a few simple dos and don'ts, you can become a pretty good public speaker.

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Chapter 10

Social Action for Busy People or

“How to Change the World in an Hour a Month.”



Photo of “Yes on Proposition 99” campaign button by Andy Aligne, with permission.

The US has made huge progress in reducing cigarette smoking. This is a monumental public health victory that saved millions of lives. Yet you probably can't name any generals of the cigarette war. **The tobacco control movement was a grassroots phenomenon involving thousands of people advocating city by city, county by county, state by state.** As a medical student, I stood on street corners handing out leaflets in favor of Prop 99, which was a referendum for a 25-cents per pack cigarette tax in California. Hundreds of volunteers across the state worked to get the word out. That ballot initiative passed and started a trend of the tobacco industry losing against public health advocates. The tax funded many things including a humorous billboard with a man saying "Mind if I smoke?" and a woman answering "Care if I die?." This counter-advertising had a significant effect on smoking in California, and the general approach was then emulated nationally.

You do not have to make headlines to make a difference. **Whatever little bit you do helps to influence what others will do.** Whatever behavior you want to see more of in the world, doing it yourself is one of the best ways to make it spread. Everything counts. Want to see a more physically active society and fight global warming? You could ride a bicycle to work.

What will you commit to do? The rest of this chapter offers a menu of options. No one expects you to do all of them. Even the simple ones can be very difficult. The point of listing a bunch is to help you find one that resonates with you, so you can commit to doing it regularly going forward. Nobody is going to do all of these things. So don't feel bad if you just pick one easy one. I leave the hard options in because every now and then someone gets inspired and does one and that's a good thing.

Activities That Take Less than 1 Hour per Month

Vote!!! Very few people vote, so your vote makes a huge difference. Where I live, it's common for only 5-10% of voters to turn out for local elections. VOTE! Seriously. VOTE! If you can't get to the polls on election day, some places let you vote early, or by mail. Whatever. Vote!

Donate to a political campaign or a non-profit organization. Donating will obviously cost you money, but takes almost no time.

Have a resource guide of CBOs in your community that you can refer people to. Or just know about 211.

Choose to **use the media wisely**: What do you listen to? Watch? Subscribe to? Look at on social media? Real news is worth paying for.

Sign up for newsletters.

Practice "Passive Activism". There are many one-time decisions that matter: where you live, how you get to work, etc. All of these are decisions with community health impact. Maybe other factors are more important and that's okay, but my experience is that many people never even think of this angle. Where you buy a house determines where your property taxes go, and what the school quality will be in your town as well as in neighboring districts. What kind of vehicle you use affects air pollution, global warming, pedestrian safety, fitness, etc. Depending

on your circumstances, you could choose not to have a car at all, or to have a small, efficient one. That one decision then sets the default for your daily impact for years to come.

Vote with your shopping dollars. You can use an online shopping portal that sends a donation to a charity you choose. This doesn't cost you anything extra but can add up to a big difference when you consider all the online shopping you do. Or you could reconsider all that shopping. "Consumer" choices all have social implications. Some clothes are made in sweatshops engaging in horrible exploitation of children, while others are not. Some retailers pay less than a living wage so that they are contributing to poverty and their employees' salaries are subsidized by Medicaid and WIC. The political implications of your purchases can't be the only factor in your spending decisions, but being aware of them can sometimes offer pain-free ways of making a difference.

Power Letter Writing. The easiest way to write a letter to your government representative is to have someone else write it for you, then sign it, and send it by clicking a button. Such a service is easily set up by signing up with an organization you support. They will keep track of important issues and do much of the work for you. Writing "Thank you" notes for positive acts is very much appreciated. Catch a politician being good!

Activities that Take 1 hour a Month

Write a Letter to a Public Official. Your purpose should be stated in the very first sentence so that your issue is clearly identified. If you are writing to support or oppose a bill, reference the number and name of the bill at the very beginning. Only one issue per letter should be addressed, and you must do this concisely. You may be outraged or frustrated, but try to disagree agreeably if you want to increase public civility.

Write a Letter to the Editor. Compose your letter so that it is brief and clear. If you are inspired to respond to an article, do so as soon as possible. If you are offering a criticism, you should also present a possible solution to the problem you have identified. Support your solution using logical arguments, your personal and professional experiences and expertise, and some kind of emotional hook. Humor is often good.

Testify before Official Bodies (courts, legislatures, etc.) You can find out about sessions open for public comment by reading the newspaper or by being on an email list for local advocacy groups. Testifying at a county legislative meeting takes a couple of minutes - at most a few hours if you stay to listen to the other people.

Gaining Representation on Boards and Councils Do you know and understand how decisions are made in your community? To gain representation you first need to find the right agency you feel would support the voice of your issue. Ask about becoming an advisor to the program. If you actively participate in the meetings and involve yourself in the discussion, the meeting has the potential for excitement, and not boredom. Be polite, but do not allow others to take advantage of you or put you down. Boards of agencies often meet for about one hour every 3 months.

Activities that Take More than 1 Hour per Month

Be a spokesperson. Serve as a spokesperson for a CBO you support. By partnering with a CBO, you can become informed about important legislation and give a boost to their advocacy efforts without having to do all of that from scratch yourself. **Campaign.** The next time an election comes around, don't simply sit back and watch what is happening from a distance. Get involved! Study the candidates and their issues by reading and watching their debates. Then choose a candidate and find out how you can help.

Register Voters. You may be able to get mail-in forms from your registration office. In some instances, you can register voters on the spot online. Let people know about absentee ballots, etc.

Apply for Grants. If you want to help launch some kind of project, you'll probably need financial support. You might be surprised at how much grant money is available for your project. All you need to do is to conduct a bit of research to find what is out there.

Be the change. There's a lot of interest the past few years in doing something about racism and increasing equity in the US. According to decades of research on schools in America, the main thing influencing the achievement of children in a school-district is the other children. School systems with concentrated poverty tend to do poorly. This is not because poor children can't learn. In schools with at least 60% middle-class kids, the poor kids do way better and the middle-class kids still do well. Where I live, the school district population is 95% poor. This concentration of poverty exists because of decades of "white flight" out of the district. Nowadays, middle-class parents don't want to stay in the city because of the low test-scores in the schools. This is a vicious cycle. There is a steady influx of young professionals moving into my city. If they stayed in the city and reintegrated some city schools, those schools should become more successful, with all the huge long-term benefits you would expect from a powerful upstream intervention. That could start a virtuous spiral of middle-class people opting for integrated public schools until the whole city is 60% middle-class. I am not saying you have to do this, or that you should feel bad if you don't. The reason I bring it up is because, in my experience, most people have never even learned about these facts regarding what makes "good" and "bad" schools. I think if more people heard about these things, more of those who tell me they want to engage in anti-racism would consider helping to reverse the vicious cycle of school segregation. This is something that can start happening tomorrow without new laws or other system changes. I am writing this handbook, so I am taking advantage of this opportunity to get on my soap box and do my little bit to try to do some good by bringing up the 60/40 concept. **If you have an audience for a few minutes, what will you advocate for?**

Other Actions You Can Take: Advanced Activism

Volunteer a lot.

Start an organization for a cause that needs one.

Get rich and then become a philanthropist.



Run for office! Michelle Bachelet is a pediatrician who was the President of Chile-twice!

Photo of Michelle Bachelet. Accessed April 3, 2024 at:
https://commons.wikimedia.org/wiki/File:Michelle_Bachelet_headshot_2013.jpg.
Comando Michelle Bachelet, Licensed under CC BY-SA 3.0, via Wikimedia Commons

While some of the above activities are very demanding, others are in everyone's reach. You can make a difference.

{Note: I have not updated this chapter for **social media**. If you want to do advocacy there, the basic concepts still apply. But, so far, I am not impressed with the capacity for disseminating good information on Twitter/X, Facebook, etc. It is clear however that such platforms can be used as massive misinformation machines. People often talk about “going viral” on TikTok or whatever as if that were a plan, but my impression is that the odds of going from nowhere to viral with accurate information are extraordinarily low. If I am wrong and you can accomplish that and make the world better, please let me know. See Tufekci below.}

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Chapter 11

Leadership and Management



Hellberg, Anders, *Greta Thunberg*, CC BY-SA 4.0, Photograph, August 27, 2018, Wikimedia Commons, https://commons.wikimedia.org/wiki/File:Greta_Thunberg_4.jpg, <https://creativecommons.org/licenses/by-sa/4.0>

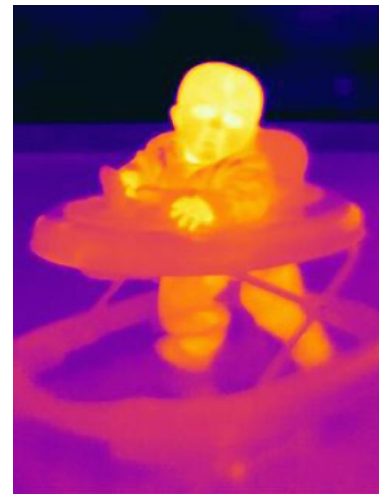
No one is too small to make a difference.
-Greta Thunberg

Leadership

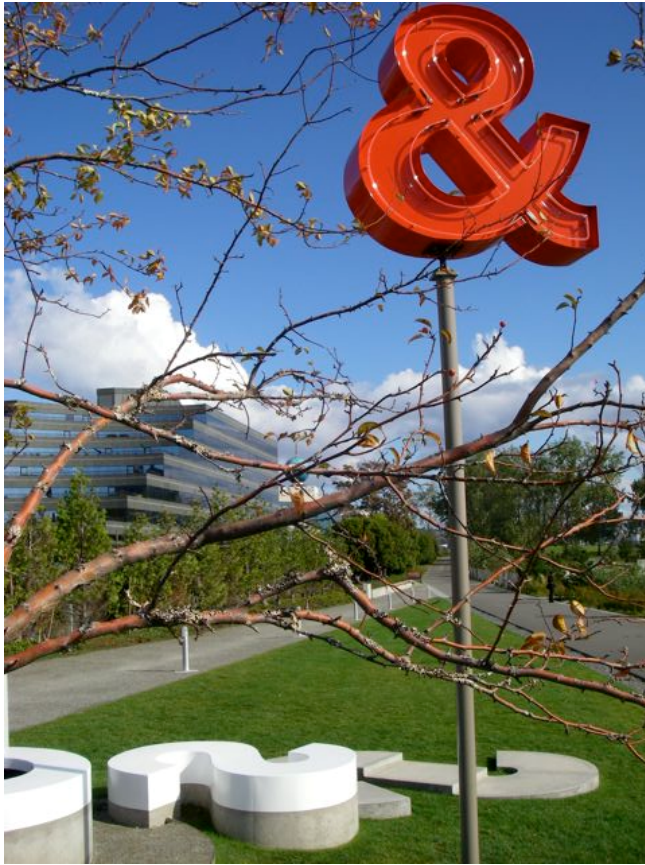
Often people think that you have to be in charge, with a title like ‘president’ or ‘CEO’ or ‘manager’ or to be a leader. But true leadership is not about titles. Just being the boss is not the same thing as leadership. This means you can lead even if you are not the boss. Greta Thunberg started an international movement and became TIME Person of the Year when she decided, as a little girl, to stage a school-strike for the climate.

Leadership is a set of attitudes and behaviors: these behaviors can be learned. You don’t have to be born a leader. One powerful metaphor is the **compass vs. the clock**. The compass represents your true North, which symbolizes what you believe in – you can call that your path, your quest, your personal legend, your values, whatever. The clock represents the rat race – The rush to be first, to get somewhere fast even if it’s not the right place to be. Following your inner compass even when it’s slower and harder going than some other path is one of the skills of a leader.

One real world manifestation of the clock mentality is the baby-walker, which used to be ubiquitous. The popularity of walkers was based in part on the dubious idea that they would help kids learn to walk sooner. Walkers have more or less disappeared because they led to many injuries of kids hurtling down driveways, stairs, etc. They are a good symbol of the problem with trying to do things faster by rushing or forcing. There are many books and courses and gadgets to help people with **time management**. But leaders focus on effectiveness vs. efficiency. They prioritize important goals instead of worrying about rushing to do everything all the time. As management guru Tom Peters said, “There is nothing as useless as doing efficiently what should never have been done in the first place.”



The difficulty in prioritizing is that **you have to say ‘No’** to some things. It would be easy if your choice were always between the greatest project in the history of the world and the dumbest most evil thing you ever heard of. But usually, you must choose between numerous good options and decide which one is the best. This is where the phrase ‘The good is the enemy of the best’ comes from. So, you’ll need to tell people stuff like “That sounds like a great idea, but I’ve just got too much on my schedule already... Maybe at some point in the future I will have time to commit to that appropriately.” People will understand. You can’t say yes to everyone and everything.



Nevertheless, once you are comfortable saying 'No', look for **the 'Magic of &.'** What does this mean? Let's say you want to do a program for inner-city boys to keep them out of gangs. The CBO you'd like to work with needs a program for girls. You could just say No and walk away, or you could look into whether the program works for both boys & girls. If it did, that would be a both/and instead of either/or. Not boys OR girls, boys AND girls. Sometimes a win-win won't be possible and that's okay. But very often IT'S AN OPTION that we miss because we just aren't contemplating the possibility. Beware of false dichotomies. Don't assume things are either/or. 'Magic of And' is also called the 'Third Way' beyond the two ways of Yes vs. No, or You vs. Me. It is the win-win instead of lose-lose or win-lose.

Photo by Andy Aligne, with permission.

Management through consensus

Management is different from leadership. Management is taking care of the day-to-day processes to move toward your vision. For community health projects, this generally means working with CBOs. In community-based organizations, there is a lot of group-based decision making. In some situations, voting occurs. But even then, there is usually consensus-building before the vote. Sometimes it is like being on a jury that needs a unanimous verdict before action. Building consensus can be time-consuming, but when done properly it aligns everyone's energy and greatly enhances the group's effectiveness. Exactly how to build consensus will change with each group and each issue, but it **starts with listening** and understanding each person's aims. Respect differences between individuals. Other people see the world differently from how you see it. This diversity is a strength because different people bring different assets to the team. Patience is necessary. Especially if you are partaking in the early formation of a group like a community coalition.

Facilitating meetings is a skill you can develop. I like the word '**facilitator**' because it emphasizes making the meeting easier for everyone else. Meetings should not be held just so the leader can give everyone else a message: that can be done by email. The point of a meeting is to have a discussion. The "leader" facilitates that by listening, giving everyone an opportunity to speak, and then reflecting what others have said while trying to put the ideas together.

Effective meetings end with action items that specific people are responsible for and that get sent out to the group along with the date for the next meeting. A bulleted list is sufficient. Long detailed minutes of everything everyone said are generally not useful. Ideally, sending out the action list is done during the meeting. **Making sure the follow-through emails happen is often a major difference between a successful project and one that sputters and fails.**

If you follow the tips in this chapter, you may become an authentic leader and see your project moving forward. As this happens, it is important to stop now and then and **CELEBRATE SMALL SUCCESSES!**

More leadership quotes:

Don't ask yourself what the world needs. Ask yourself what makes you come alive and then go do that. Because what the world needs is people who have come alive.

-- Howard Thurman (Mentor to Dr. Martin Luther King Jr.)

"A leader is like a shepherd; he stays behind the flock, letting the most nimble go out ahead, whereupon the others follow, not realizing that all along they are being directed from behind."

-- Nelson Mandela

"Management is doing things right; leadership is doing the right things."

--Peter Drucker, management guru

"Leadership is the art of persuading the other fellow to want to do what you want him to do."

--Dwight Eisenhower

"If you want to build a ship, don't drum up the people to collect wood and don't assign them tasks and work, but rather teach them to long for the endless immensity of the sea."

--Antoine de Saint-Exupery

"If a pretty poster and a cute saying are all it takes to motivate you, you probably have a very easy job. The kind robots will be doing soon."

--Despair.com

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Chapter 12

Grant Writing and Fundraising



US currency: Image originally uploaded by w:User:J.J., Public domain, via Wikimedia Commons.
Accessed April 3, 2024 at: https://commons.wikimedia.org/wiki/File:USCurrency_Federal_Reserve.jpg.

“When you let go
of trying to get more
of what you don't really need,
it frees up oceans of energy
to make a difference
with what you have.”

— Lynne Twist

Money and Mission

Many people are reluctant to talk about money, let alone to go around asking strangers for donations. This is unfortunate because it generally takes money to run community programs. In the non-profit world, this is expressed as the phrase **“No money, no mission.”**

People doing community projects often feel they should volunteer and that it's somehow shameful to ask for financial help. In my experience, some of this has to do with negative attitudes towards money and/or rich people. While greed is a sin, money itself is value neutral. It's like fuel you put in your car. If you use the car to run over little old ladies, that's evil; but if you use it to volunteer for Meals on Wheels, that's a good thing. Don't feel bad about asking for money to do Good Work for the community! **The money is there being given away, but is frequently wasted on things that don't work.** You have a right and a responsibility to divert those funds to things that do work to help people!

Looking for Money in All the Right Places

The place to start looking for money is with your passion. Other ways to say this are “do what you love, the money will follow” and **“YES MISSION, YES MONEY.”** This is not as crazy as it sounds. Unless you're a great actor, selling something is just a matter of communicating your honest enthusiasm: if you don't believe in something, you can't sell it -- but if you do believe in it, then you're selling it just by talking about it.

Tell everyone you know about your project, and don't feel bashful about telling them it needs money. **Funders are looking for opportunities to give their money to you.** They routinely release public offers of free money. These are known as: Calls for Proposals, Requests for Proposals, Requests for Applications, Notices of Funding Availability and Program Announcements – I'll abbreviate all of these as RFPs. These can be found by checking foundation websites, reading professional journals, signing up for email lists (ask your librarian), etc.

There is a danger though in getting too focused on RFPs and twisting what you want to do to fit the requirements of a particular grant. You don't want to put the cart before the horse and prioritize money before mission because that mismatch can lead to the kind of ineffective programs we are seeking to avoid becoming. **It's also not fun to let your life slip into unfulfilling “RFP-chasing.”** If you can keep your focus on your passion about your mission you can avoid that fate. You may not need a grant. Einstein didn't have grants to make his great discoveries. Florence Nightingale didn't have NIH funding to revolutionize nursing and public health. If you don't need a grant, don't apply for one.

Basic Grant Components

You already put together the basic components of a grant when you made a project plan, abstract, slide show or poster about your project. See, the first part's done. Wasn't that easy? If

you haven't done any of those things yet, don't worry. Although grant application forms are all different, they share some simple elements.

Title: This should be clear and short.

Cover letter: This is basically just a fancy packing list for what you're sending to the funder. Don't try to sum up the whole proposal here, but do include a line about how your project is such a perfect match with their mission.

Background: You may want to **do this last**, even though it's what people will see first when they look at the grant itself. You may have many pages of background research that you've written up. In general, you don't need all that here, but do make sure you have your facts straight: double-check statistics, references etc. This is where you convince people that they should bother to read the rest of your proposal. In general, you want to make 3 points:

1. Bad problem
2. Big problem
3. Gap that you are going to fill. (If it's a research grant, you're creating new knowledge; if it's a service grant, you're providing a needed good solution to the problem.)

Goals: Big picture aims.

Objectives: Specific measurable outcomes you will achieve. It is very important to pick ONE primary outcome that you will use to determine whether your project has succeeded or failed.

Methods: This is where you make the case that you can accomplish your objectives. Some theory is fine but this needs to be practical: Who Will do What Where When How? Also mention how you will evaluate success. A timeline is nice here. You may want to consider making a "**dummy presentation**" with tables and diagrams as if you'd already completed the project; you won't include that in the grant usually, but it can be very useful for helping you to think through all the steps between start and finish. If you do put it in the grant, just make sure to label it properly.

Budget: The budget is the most mystifying part of grant writing for beginners. Ask early for help with this. You will need to make some educated guesses about what things will cost. One tactic that helps is differentiating between fixed and variable costs. Fixed costs are what you need just to "open the doors" regardless of whether you actually perform any functions. Variable costs increase as you do more. Hence, once you've covered your fixed costs, you can scale back your objectives and the variable costs to fit the budget limit. Think very hard about what you can get for free (in-kind donations) or from other funding sources. Include those items in your budget as

dollars already covered. **Funders like to see that you're being resourceful and that they're not the only ones investing in your scheme.** A "budget justification" is where you write out how spending money on the budget items is necessary for achieving your objectives. Even if this isn't specifically asked for, it's nice to include a few lines for non-obvious expenses.

Conclusions / Implications: This should cover the main expected outcomes and their "So what?" implications.

Summary: For long grants, this may be all the reviewers will look at. Therefore, make it very clear. If it's allowed, use bullets, graphs, etc. Avoid jargon.

Appendices: If allowed, this is where you throw in all the stuff you think will help your cause but that doesn't fit into the application itself. You may want to put in brochures, letters of support, CVs, etc.

The Winning Grant

As with everything else in life, getting grants involves luck, connections and timing, but there are factors that you control that can increase your chances. In addition to the steps above:

1. ***FOLLOW ALL THE DIRECTIONS!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!*** Seriously folks, follow all the instructions from the funders in the RFP. If it says "24 pages max" don't send 25. Many grants do get rejected over such trivial details. Make sure you have the right font and the required signatures, that you've answered their specific questions, that you're ready ahead of the deadline.
2. Talk to the funders; ask questions. Don't pester them continually, but one or two calls to save everybody time in the long run will be appreciated. Make sure your alignment with the funder's goals is very obvious throughout your application. Include information to convince them that not only is this a good project but that you specifically are the right person(s) for the job.
3. Have a plan for sustainability and long-term impact of the project.

Fundraising is more than grant-writing.

If you need money but writing a grant is not going to work for you or your project, there are lots of other ways to raise funds. Very few people are sociopaths. Most want to help others and feel good about making the world better. Being generous makes them happy. Not everyone has the means to donate a million dollars, but there are millions who can donate \$1.

If you do good work and document it and tell your story, then you can make a happy connection between your donors and your project. How you connect depends on you:

- Crowdsourcing
- Holding an event
- Going on local media to talk about your project or event
- Asking friends, family, etc.
- Being ready with an “elevator pitch” for any stranger who’ll listen to you.

Sustainability is more than fundraising

Ideally, sustainability means the project is so successful that it gets institutionalized into routine practice and becomes a part of normal operations. Sometimes you have projects that make money and are thereby self-sustaining. Other projects have a one-time cost for start-up and then can continue indefinitely for free with volunteers. Ultimately you should hope to make your project superfluous by eradicating the problem the project was designed to address. Unfortunately, that doesn’t happen very often and so if you do manage to implement an effective program, you want to take it to scale so you can do as much as possible to diminish the problem. In my experience there are 5 common elements of projects that achieve long-term success. This **Project Pentad** is illustrated in the following case study.

CASE STUDY: Project TEACHER and Rochester Coping Power



Photo by Andy Aligné,
with permission.

Dr. Caroline Boxmeyer visits the Rochester “Project TEACHER” team to train them in providing Coping Power, beginning a long partnership.

Project TEACHER was started by Pediatric and Medicine/Pediatric Residents in Rochester, NY, which at the time was the murder capital of NY State. The murder perpetrators and victims were mainly teen boys. After researching the topic, the residents found that one of the main predictors of adolescent violence was aggressive behavior earlier in childhood. They looked for **evidence-based programs** that decrease long-term problem behaviors and found Coping Power. Coping Power is an educational intervention for behavior change, but it doesn't just give information, it gets at the emotional factors underlying conflict and teaches children skills that they are not acquiring elsewhere for how to cope with life's difficulties without resorting to violence.

With the help of mentors, community partners and a small grant, they brought it to one inner city school in 2006. 7 years later it was in 17 schools. So what did they do to achieve that kind of sustainability? They got more and bigger grants, but the important lesson here is that sustainability is about more than money.

The residents definitely started with the **passion** to do something about the issues of youth violence. When your passion is real, people can tell and you can find other people who will be your champions in the community, and then you can build real **partnerships** with CBOs.

And then you work together to plan and you start by **piloting**. And you may find that things go wrong your first year. That's okay. That's why you did a pilot. So you debug your program and then you pilot it again. Then you implement it "for real" in one place. Then maybe after that you think about expanding to several places. As they adapted their intervention, they consulted with the creator of the program so that they maintained fidelity to its core components while customizing its delivery for local circumstances. As you're going along, you're measuring results and making sure that you're doing high quality work. One of the most important features of the project **plan**, and one of the reasons for selecting Coping Power was that the program works on a train-the-trainer model. That is to say, once the residents got trained, they could train other people. They didn't have to pay over and over to send every person involved to get trained.

They talked about their program, **promoting** it, bringing on allies as they went. Selling it not only to funders, but also to local bigwigs like the Mayor and the Superintendent of the city school district.

Because they measured results (using found data!) they were able to document a dramatic decrease in suspensions, referrals to the principal's office, and teacher reports of aggression in the whole school after Coping Power began. These impressive results helped tremendously to get "buy-in" from teachers, parents, administrators, and students. Then it was easy to get letters of support for grants, etc. and the reputation of the program spread by word of mouth from teacher to teacher, vice principal to vice principal, to other schools and also to funders like the local United Way. Other programs including one called PATHS, which was for all the kids in the school, were going on at the same time and these complemented Coping Power.

If you're doing community work for the right reasons and you maintain high standards of quality to maintain good outcomes, things will still go wrong and you'll still have to apply for grants. But you'll be surprised by how much money just appears that you didn't even ask for and how much the program grows organically on its own. For example, appearing in the newspaper generated thousands of dollars in unsolicited donations.

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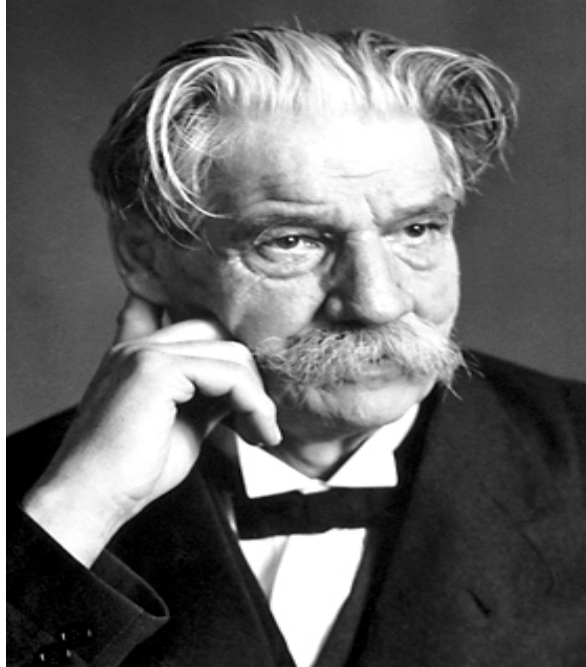
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Chapter 13

Behavior Change



Dr. Schweitzer: Nobel Foundation, *Albert Schweitzer 1952*, Public domain, via Wikimedia Commons,
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*“Example is not the main thing in influencing others.
It is the only thing.”*

-Dr. Albert Schweitzer, 1952 Nobel Peace Prize

The importance of behavior change

“Lifestyle” is a major determinant of health. Smoking, for example, has been a contributor to cancer, heart attacks and other deadly diagnoses over the last century. So, if we want to increase health, we need to decrease dangerous behaviors like cigarette-smoking. What’s the best way to accomplish that?

The health information model

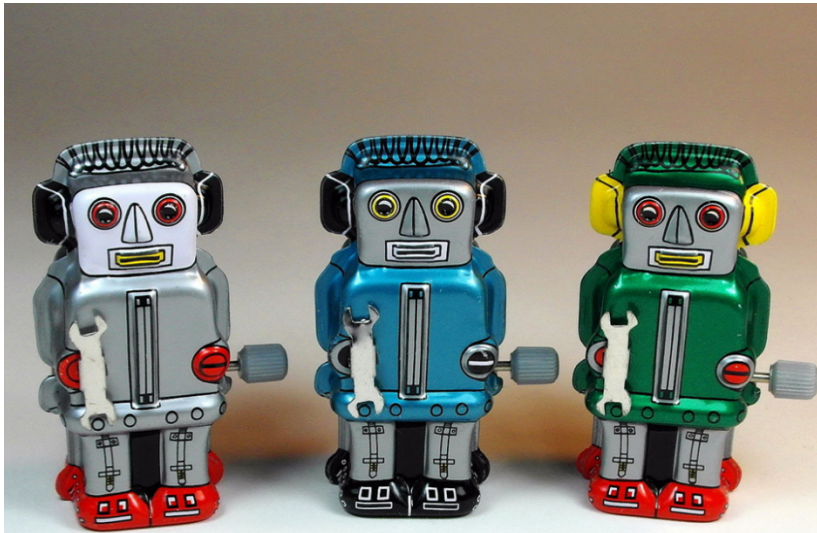


The first impulse of most people interested in doing a community health project is to go out and teach people what they should be doing differently, whether it’s eating, sleeping, smoking, parenting, sex, posture, or whatever. The underlying assumption is that people lack the knowledge about how to be healthy. This is the Health Information Model. I refer to it as the “people are robots” approach because the general idea is that providing accurate information will reprogram people. This seems plausible. If you’re reading this, you’ve probably endured many years of education and so you hope it was all worthwhile. You probably also do a lot of sharing health-promotion advice. **The problem with this health education approach is that it often doesn’t work.**

People are not robots.

The fact is that knowledge by itself is usually not enough to change behavior. Think about smoking. When it became generally known in the 1950s that cigarettes caused lung cancer, some people stopped smoking, but overall smoking kept going up. Even today, when everyone knows that smoking is toxic, many people still do it. So, knowledge is helpful and may be necessary, but it’s not sufficient for public health impact. You can’t change human behavior just by dumping information on people.

If you are going to do health education, remember First Do No Harm and try to make



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sure you are giving accurate, evidence-based advice. For example, the biggest official dietary advice for decades was to avoid fat, especially saturated fats. This led institutions and individuals to replace animal fats in food with sugar and with vegetable-based trans fats. Both substitutions are thought to have increased the risk of disease. Trans fats were estimated to be

causing about 7,000 fatalities a year in the US. They were eventually banned by the FDA in 2019. “Heart-healthy” foods that are “low-fat” or “non-fat” but full of sugars are thought to be a major factor in the obesity epidemic. **You can’t look up everything on every topic. But you can go deep in one area and be the expert.** So, if you are going to have this be your thing and put a lot of energy into a project of giving out information, then try not to kill people with it.

KASH Mnemonic

If knowledge is nice but not enough, then what else do you need? A behavior change acronym I like is **KASH** (“With respect to behavior change, the money is in the **KASH**”): Knowledge, Attitude, Skills, Habits/Health. This is not based on any particular behavior change model. I just like the acronym and the bad joke – and I think it’s useful.

In this framework, to change smoking behavior, for example, rather than limiting oneself to lecturing about lung cancer (*Knowledge*), one could:

- Use counter-advertising to spread the message that smoking cigarettes makes one a pathetic, unsexy, duped “sucker” of the tobacco corporations (*Attitudes*)
- Give people nicotine replacement treatment to help them quit (*Skills*)
- Pass clean indoor air laws that alter societal norms for where it is possible to smoke (*Habits*)

This kind of approach has been remarkably successful in improving outcomes (*Health*)

Therefore, your intervention design and your evaluation should try to go beyond Knowledge, Attitudes and Skills to check that you have changed Habits and produced better Health. Normally, people would talk about Behaviors here as opposed to Habits. I prefer Habits

because it emphasizes that you want to produce routine, long-term behavior change. Also, it's hard to say "KASB."

Beyond the Individual

Another useful concept is that of barriers to change. Instead of just thinking about convincing people to engage in good behaviors, we could make it easier for people to change. For example, helping people who want to quit smoking by giving them effective cessation support is much more gratifying than saying "you should quit smoking" to all smokers. (This also fits with "Stages of Change" brief motivational interviewing.) **In addition to lowering barriers for healthy behaviors, we could raise barriers for unhealthy behaviors.** Actions taken along these lines include community-level advocacy increasing cigarette taxes or establishing smoke-free restaurants.

A general lesson from the tobacco control experience is that behavior change at the individual level is generally much more difficult than at the population level. Some of the reasons for this are practical: it's easier to put up one billboard that a million people will see than to visit with a million people individually. But also, as we learn more about human psychology from scientific experiments, it becomes clearer that **people are social animals** with learned and hard-wired behavioral response patterns that involve feedback loops connected to the behaviors of other people. Perhaps one of the biggest things doctors did to fight tobacco was to quit smoking *en masse* before other people did. Example!

Motivational psychologists are paid big bucks to figure out how to manipulate us every day into shopping in a certain way and they are very good at what they do. Because people are *not* robots, the "hidden persuaders" are not 100% effective. And while we would all like to think that we personally are not affected by marketing, the evidence indicates that we are (those pens from the drug reps really did change prescribing patterns; that's why drug reps aren't allowed to sponsor med school lunches anymore). If "**people don't know why they do what they do**" a behavior change approach based solely on logical appeals to individuals is not likely to work.

The Prop 99 campaign in California was a successful tobacco control initiative. It used **counter-advertising, designed to undercut the emotional sales pitch** of the cigarette companies. For example, at a time when cigarettes were advertised all over the world by the Marlboro Man (a rugged cowboy character), Prop 99 bought billboards with pictures of cowboys riding horses and saying stuff like "I miss my lung, Bob." This was attention-grabbing. It is *not* a bunch of medical info about cancer and the dangers of smoking. But it is effective at communicating that cigarettes will do the opposite of making you rugged, attractive, and independent.

Tobacco Control is one Model

Positive change in health behaviors is difficult but it is very feasible, especially over the long-term at the population level. The public health approach has also been highly effective for decreasing infectious disease deaths (sewers, clean water, food inspection, etc.), motor vehicle deaths (seat belts, crumple zones, drunk driving laws, etc.), and other huge

problems. These upstream preventive efforts are not as dramatic as downstream heroic rescues and so they are somewhat invisible and thankless, but they matter a lot for improving health.

For whatever behavior change project you're contemplating, think of tobacco control as the model. **The tobacco control movement, which was a bottom-up grass roots phenomenon, helped to change the social norm.** People used to smoke everywhere: in airplanes, restaurants, etc. Doctors used to smoke in the hospital on rounds. Schoolteachers used to force children to make clay ash trays to take home for Mother's Day. These things are hard to believe now because there has been a huge cultural shift in what is acceptable behavior in a relatively short time. Cigarette smoking prevalence has declined dramatically. And that shift will save many lives. If we look at studies of contestants in the "Biggest Loser" TV show, we find that people who lose weight from diet and exercise generally gain back the weight even if they maintain strict caloric restrictions and grueling exercise regimens. Another reason to think that lessons from tobacco might be particularly helpful for obesity control is the overlap between Big Tobacco and Big Food. At one point, as Big Tobacco started losing lawsuits, they decided to diversify, and they bought companies that make soda pop, cookies, beer, meat, cereal, etc. There's evidence that they used the same tactics as with cigarettes to spread the pandemic of junk food. Remember the 5 shuns from an earlier chapter? What would they look like for obesity control?

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Chapter 14

Global Community Health



USAID Africa Bureau, *Children Receive Plumpy'Nut Nutritional Aid in Ethiopia*, Photograph, 2008, Public domain, via Wikimedia Commons. Accessed April 10, 2024 at: <https://commons.wikimedia.org/w/index.php?curid=21460209>

*“One incontrovertible fact -- **Plumpy'nut and other ready-to-use therapeutic foods save malnourished children's lives.** The paste is so effective because it requires no preparation, is easy to use without special instructions, and it can be given to malnourished children in their homes.”*

--UNICEF

Note: I've avoided using the terms “Third World” or “developing nations” in this chapter. A newer term is “Global South”, but I find that confusing because it's not about latitude. The issue is entrenched systemic poverty, so that's what I refer to.

Why do Global Health?

The general principles of community health are relevant not just locally, but also globally. **If socioeconomic factors are important determinants of health in the United States, they are a hundred times more important in impoverished countries.** This can make the challenges seem insurmountable. But there are several reasons for going, including benefits for the physician as well as for the “distant needy.”

- 1) International health volunteers often have profound life-changing experiences from witnessing the effects of extreme poverty. Seeing children starving in poor countries may force you to consider deep philosophical questions about unfairness in the world, and this can help to give you a clearer perspective on what’s important in life when you get back. If it helps to motivate you to rectify international injustices then that’s a good thing. It is, however, often considered a bad thing called “**culture shock**” and you should be ready to deal with it, preparing for it ahead of time and debriefing when you get back.
- 2) You may see maladies ranging from measles to malaria, which are now rare here.
- 3) Also, you could learn how to problem-solve cost-effectively without relying on many of the high-tech diagnostic tools or treatment options normally available here.
- 4) You could provide emergency help around the time of a major disaster like an earthquake, hurricane or a war. For people in these disaster situations, access to basic first aid can, at that particular time, mean the difference between life and death.
- 5) Another kind of international work where you can make a lasting difference is where you partner with a local NGO (non-governmental organization), especially if you get specialized training before leaving on how to do things that are effective and cheap and sustainable in poor countries. It takes a lot of planning ahead to devise interventions appropriate for situations where people do not have electricity, x-rays, a cold chain (which is the ability to transport refrigerated items over long distances), etc. **A successful international health experience even more than a successful local community-based experience depends upon humility, partnering with a well-run NGO, planning for how to do effective interventions, and preparation before starting.**
- 6) Sometimes people do go and spend significant chunks of their lives living and working in poor countries. If that is what you want to do, you should find a facility abroad where a proper role model will be there to teach you and mentor you.

Medical care is important and desperately needed in poor countries. In this chapter, though, we will be emphasizing community health interventions because those tend to be underemphasized otherwise in discussions of global health.

What to Avoid

Although the worst thing typical on international electives is a bout of diarrhea, there are horror stories of getting shot at or lost in the jungle. If you accomplish a lot while you are there, then maybe such hardships are worth it, but if you come back feeling that you were useless, then the whole expedition was a huge waste.

An international health elective needs to be more than just an adventure

vacation. Unfortunately, trips that fail to deliver substantive help are common. One of the main problems is going to a poor country thinking it will be the same as volunteering in a clinic at home. This is a recipe for frustration. The lack of familiar tools and the overwhelming disease-causing conditions will thwart your efforts. Moreover, all the medical tourism leads to critiques that global health education is overall unethical. Among other reasons, the money spent on flying you to a distant land could buy a ton of Plumpy'nut and save many children's lives.



The Myth of Tropical Diseases

Earlier in this book, we learned about the Epidemiologic Transition: the causes of death shifted from infectious diseases that mainly affect children to chronic lifestyle diseases that manifest in older adults. **Many poor countries now are hit with the double disaster of still suffering from the pre-Transition infectious diseases of lack and then also being affected by the post-Transition diseases of excess like smoking, obesity, etc.**

Sometimes epidemiologic patterns can seem upside-down in poor countries. For example, whereas in the United States asthma is much more prevalent in poor children than in rich children, in poor countries asthma is much more common in rich children. This is because, as far as we know, asthma is a disease of excess, or “Western Civilization”—found where you have an excess of pollution, technology, sedentariness, living indoors, etc. In rich countries, the people who are most exposed to those factors are poor people living in under-resourced urban areas. Whereas, in many poor countries, many of the poor people are still living in rural areas and those who have an urban modern lifestyle are the richer people. Of course, all that is changing rapidly.

Global Health is often referred to as “tropical medicine.” But **“tropical diseases” usually have little to do with latitude and are actually diseases of lack.** Malaria, for example, used to be endemic in the U.S., Canada, England and even northern Russia. The disease is only “tropical” now by default, because improvements in living conditions (drainage, workdays, clothes, housing, air-conditioning, window-screens, etc.) helped it to disappear from the rich countries. So, it's good to know about various drugs for exotic bugs, but if you want to get at root causes and have a big impact, it's important to see the bigger picture.

Eliminating Diseases of Lack

Fortunately, we know a lot about what made the pre-Transition “Old Morbidity” disappear: economic growth, sanitation, improved nutrition, etc. The countries with very high mortality now are the places that are still lacking the basic elements of a public health infrastructure. According to the United Nations, **3 million children die each year from malnutrition**. This is down a lot from previous decades, but it’s still a big number. These horrific numbers of child deaths have been declining, but there are fears that global warming and other factors will be driving them back up.

It is important to understand when talking about “causes of death”, that the underlying root cause may be something else. For example, **with an infectious disease, the real culprit may be malnutrition, which weakens the immune system**. Remember to always “go upstream.” A dramatic example of this is a 2004 placebo controlled randomized trial published in *The New England Journal of Medicine* that showed the effectiveness of a pill for stopping progression of clinical AIDS. What was this amazing pill? It was a vitamin.

This sort of result is predictable in poor countries where people still lack food and clean water. Almost two million children under five years of age die each year in poor countries from **diarrheal diseases, ninety percent of which would be prevented by access to clean water and sanitation**. A 2005 study in the *Lancet* showed that giving plain soap to people in squatter settlements in Pakistan decreased pneumonia in children under five by more than fifty percent! Should we spend very limited resources on building hospitals staffed with infectious disease specialists and outfitted with the latest drugs and machines, or does it make more sense to give people soap? Does it make even more sense to equip people to make soap?

More recently (2023), I went to a research meeting where there was a poster about how the ubiquity of soap-making chemicals is causing burns in children. Therefore, while soap-making does provide sanitation for the community and a way for women to generate income, one still needs to monitor the results of interventions and watch for side effects.

- As we saw previously, one of the biggest determinants in the world of infant mortality is maternal illiteracy. Why aren’t we giving more girls the opportunity to learn to read?
- Malaria can be effectively prevented with bed nets that keep mosquitoes from biting people while they’re sleeping. Fancy bed nets treated with insecticide cost about five dollars. At a larger scale, malaria is reduced by structural changes that go along with general economic development (window screens, clean water and sanitation/drainage projects, scientific dam management, etc.).
- Guinea worm, which is a parasite that causes terrible suffering from elephantiasis, can be stopped with a filter that looks like a potato sack and that goes over the bucket the family uses to collect water -- when there is no better water supply than the local



Bed Net Photo, by Andy Sherman with Permission.

river. These filters cost a few dollars. The disease has been nearly eliminated. The Carter Center has been sponsoring that work.

- Trachoma is a leading cause of blindness in poor countries. A 1997 paper in the *Lancet* documented a dramatic fall (about twenty-five fold!) in a Gambian village following improvements in sanitation, water supply, education and basic health care. The study concluded, *“Of particular importance is that the decline in trachoma occurred without any trachoma-specific intervention.”*

This list could go on and on, but you probably get the point by now. **There are very cheap, very effective, evidence-based public health interventions available to address most of the major causes of death and disease in poor countries. They generally work even without knowledge of the specific etiologies of the diseases because they go upstream to address underlying causes.**

The idea that we cannot do anything about killers like malaria without expensive medicine or more biotechnology research is dangerous nonsense. Sure, a cheap and safe and effective malaria vaccine would be great, and it's nice that billionaires are investing in such efforts, which may pay off some day. In the meantime, a lot could be done right now without a lot of money. And indeed, there are success stories. **The eradication of smallpox by the W.H.O. is one of the greatest achievements of humanity.** If you could make a meaningful contribution to an effort like that, then you would be doing amazing work.

Finding a Partner

Unfortunately, it is not always easy to find out which NGOs are actually doing a good job. For example, in 2011, there was a huge scandal regarding the Central Asia Institute, featured in the mega best seller *Three Cups of Tea*. It turns out the book was mostly made up. This flabbergasted me. The tens of millions of dollars and person-hours donated to CAI could have done multiple times more good for the world under more responsible leadership. Female literacy programs are not a new idea. People have been doing these in Asia for decades. What would you feel like if you spent months preparing and then went overseas into dangerous territory working for a month with an agency that turned out to be a scam? To identify honest and effective NGOs, **you need some direct link to what is happening on the ground with the agency you want to work with.**

- Start by getting background information on your topic of interest in general and at your away site in particular. Where can you find such information? There are many books and websites that can help.
- Try to keep a broad perspective, remembering that **simple community-level upstream interventions** may have much more bang for the buck than complex individual-level downstream rescue care. With TB (tuberculosis), for example, there is a huge difference between latent and active infection. Public health measures that help to prevent latent infection from becoming active disease might be very beneficial. Going even further upstream, social measures that decrease the risk of infection could block the cycle that keeps TB endemic in a population. And what about BCG? We don't use it here, but some countries credit it with helping to conquer TB. What would make sense for where you are going?

- Once you know some general facts about the area you will be visiting, continue your planning by **developing a relationship** (email, Skype, Zoom, letters, talking to others who have been there, etc.) with your away partner who will know the local customs and be able to place you and train you so that you can be most useful.

Logistics of International Rotations

YOU NEED TO START PREPARING EARLY!

- Are there translators or crash-courses in the native language if you don't speak it?
- Are there local people involved in running the facility that you would be going to?
- Is the program sustainably adapted to the local culture and its daily reality?
- What gifts/supplies would they really appreciate?
- What shots should you get?
- Is the country on the federal watchlist of dangerous places?
- Do you need a visa? Do you need permission from work/school?
- How do you get from the airport to the site?
- Is there electricity, running water, toilets, etc.?

Helping There From Here

As we talked about early in this manual, begin with humility. The chances that you are the American savior whose medical knowledge will fix everything in some village or country are pretty small. In fact, many countries—even poor ones—have better health statistics than the US. I always ask people interested in international health electives why they don't **go to Canada or Europe to learn from those people** how to do things better here. Humor me and go through the thought exercise.

What would obviously help most would be effective programs that **address the underlying poverty in poor countries**. How what we do contributes to global poverty is beyond the scope of this discussion. But you can educate yourself about it and consider it when you vote or shop or donate.

Don't underestimate the power of advocating. Coming back to talk about conditions in poor countries can help raise awareness about what is happening there and what needs to be done. This gives a voice to these children in Africa, Asia, Latin America, etc. who have no voice here in the United States. We could do a tremendous amount of good right now with what we already know. We know people need clean water. People need food. People need soap. Etc. Etc. This is an advocacy issue. So maybe the best thing you can do to help the most people if you want to do an international elective in a poor country is to **go there with a good camera** and come back explaining what you saw to as many people as you can. And maybe you could document stories of how digging a well or giving people a net can improve health. And that kind of advocacy could be how you can use your expertise to help the most vulnerable people on the planet.

A more direct approach is to work with local refugees. Facilities dedicated to refugee care are becoming more widely available. The CDC and other organizations have developed guidelines addressing the **special needs of international refugees**. Working with this population

is a great way to learn about global health issues and help people from poor countries without leaving home.

When you make donations to charities, consider focusing on organizations that engage in effective evidence-based prevention.

Another opportunity for advocacy is to explain the facts to your friends and family. In polls, Americans think that we spend 27% of the federal budget on foreign aid. In reality, we spend about 1% and much of that is military, not humanitarian assistance. A great place to go for facts about the world is Gapminder.org. They have all kinds of animations, videos, photo essays, statistics tools, etc. Overall, their message and mine is that there is a lot of good news now! **Lots of things are getting better! And we know what to do next!** And a lot of it is very simple and very cheap, like Plumpy'nut.

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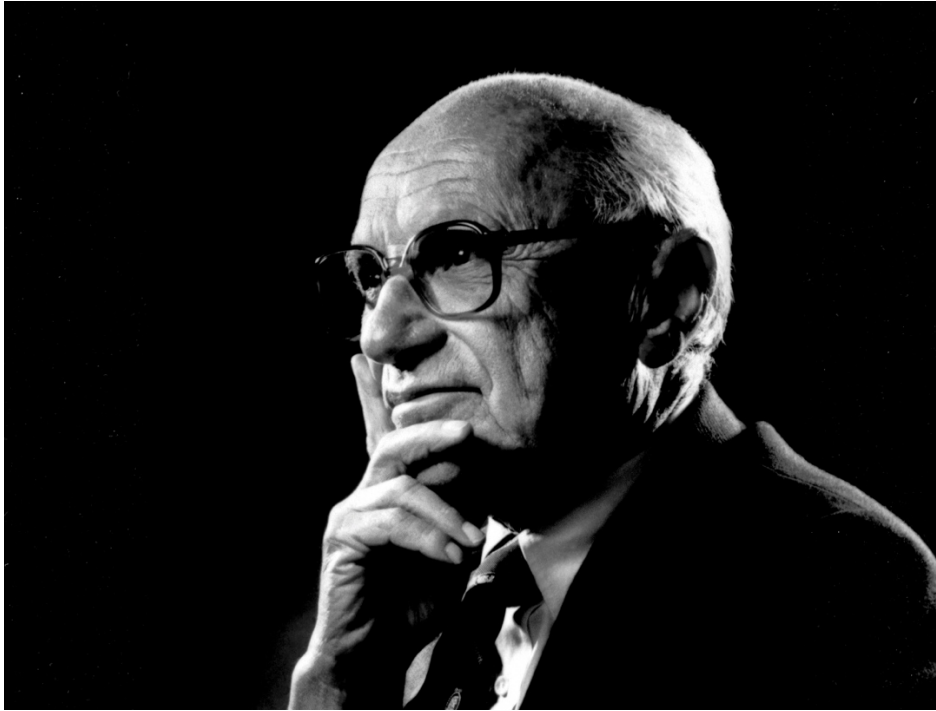
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Chapter 15

Health Systems



The Friedman Foundation for Educational Choice, *Portrait of Milton Friedman*, Photograph, 2004, (Wikimedia Commons), Accessed April 10, 2024 at: https://commons.wikimedia.org/wiki/File:Portrait_of_Milton_Friedman.jpg

“Few trends could so thoroughly undermine the very foundations of our free society as the acceptance by corporate officials of a social responsibility other than to make as much money for their shareholders as possible.”

- Milton Friedman, *Capitalism & Freedom*, 1962.

U.S. Health System: High Cost, Low Benefit

High Cost

Medical spending is very high in the U.S. In fact, per capita government health spending in the U.S. exceeds the **total** health spending in other affluent nations like Canada.

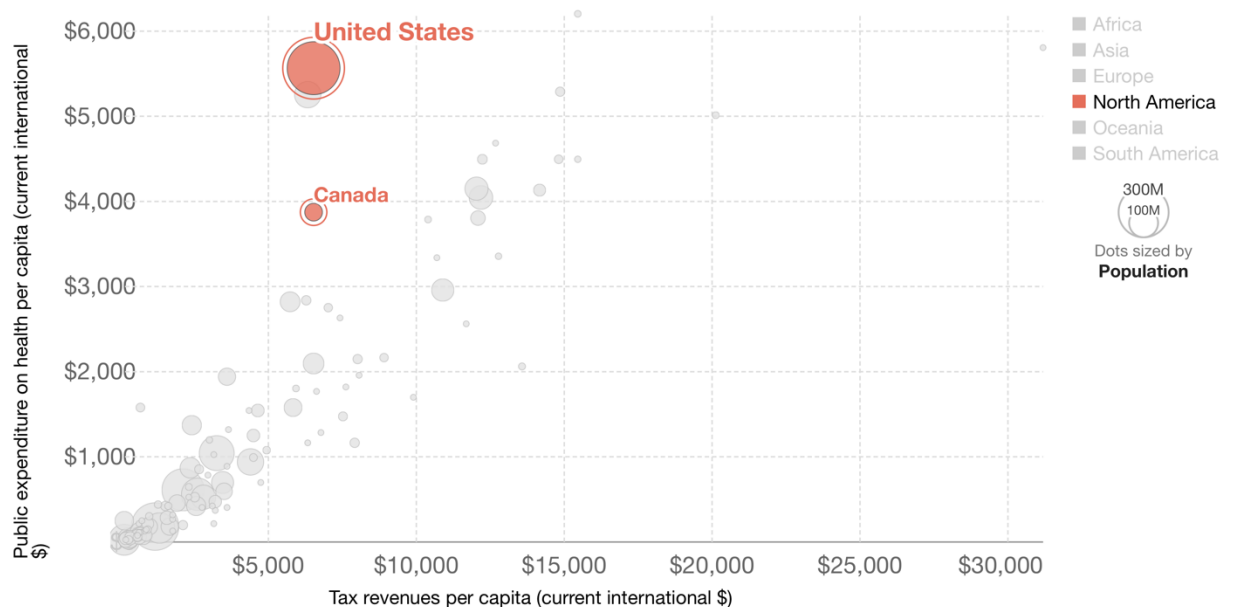
Government spending includes Medicare, Medicaid, Veterans Administration programs, as well as insurance premiums for government employees and tax subsidies for private insurance.

AMERICANS ALREADY PAY ENOUGH IN TAXES TO FULLY FUND A NATIONAL MEDICAL INSURANCE SYSTEM THAT WOULD COVER EVERYONE.

Tax revenue per capita and public health spending per capita, 2019

Tax revenue is defined as compulsory transfers to the central government for public purposes. Public expenditure on health care is defined as all the recurrent and capital spending from government, external borrowing and grants, and social health insurance funds. Both variables are measured in current international \$, which adjusts for price differences between countries.

Our World
in Data



Source: World Health Organization (via World Bank), OWID based on World Bank
OurWorldInData.org/financing-healthcare • CC BY

Low Quality

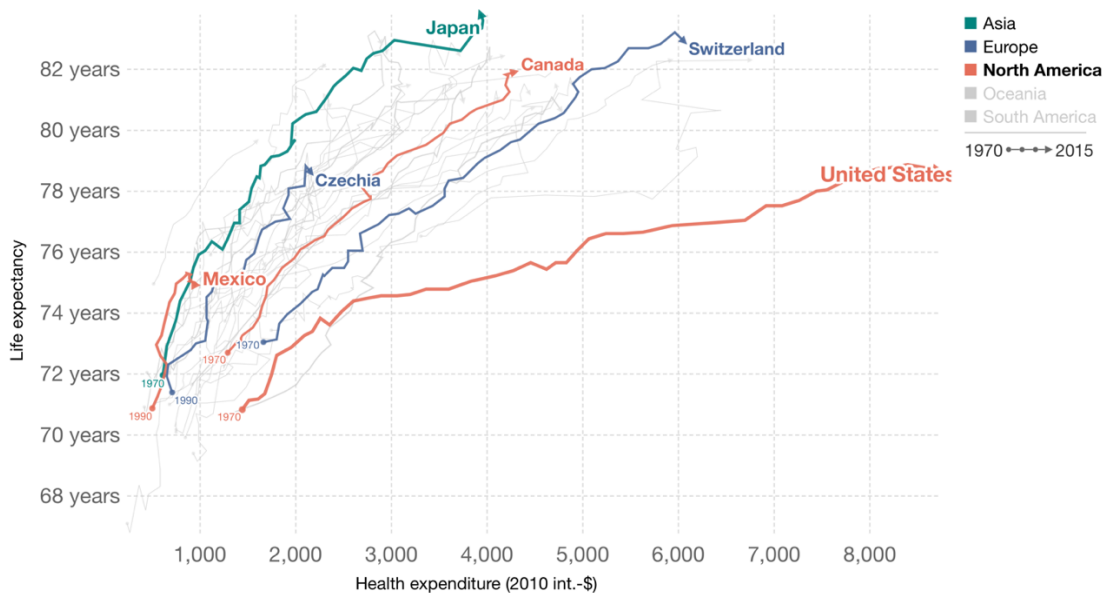
Quality of medical care is very difficult to measure or even to define. It may be true that places like the Mayo Clinic deliver the best medical care in the world to those who can afford it, but it's not clear what the evidence for that is or what it means in terms of the quality of the U.S. health system overall. As a result, the quality of health systems is usually measured by such population level outcomes as life expectancy. After World War II, the U.S. led the world in life expectancy rankings. Since then, our health gains have lagged behind those of other industrialized nations. The US, despite spending much more than other countries on medical

care, has lower life expectancy than places like Canada.

Life expectancy vs. health expenditure, 1970 to 2015

Health financing is reported as the annual per capita health expenditure and is adjusted for inflation and price level differences between countries (measured in 2010 international dollars).

Our World
in Data



Source: Data compiled from multiple sources by World Bank; Health Expenditure and Financing - OECDstat (2017)
OurWorldInData.org/the-link-between-life-expectancy-and-health-spending-us-focus • CC BY

Value = Quality/Cost

Okay. That's it. Our health system is very good at costing a lot. It's mediocre in terms of population health outcomes. Ergo, it's a global outlier in terms of (low) value. This seems like a problem to me. However, I guess it is fine if you think the point of a health system is so that a few people can make a mountain of money, or if you think it's important to take care of unicorns instead of horses.

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Chapter 16

Evidence Based Happiness



Aligne, Rachael, personal photograph by Andy Aligné, with permission.

Disclaimer: The “Evidence based” in the title of this chapter is sort of a joke.

What does this chapter have to do with community health and advocacy? Everything. It’s hard to heal others or go and inspire people if you’re all burned out.

Having said that, some readers have felt this chapter is inappropriate and that’s okay. Feel free to skip it. I am including it though because the material here has repeatedly turned out to be life-altering in a positive way. I have tried hard to stick to the best available evidence, but it’s weak, so I understand if this seems more like wisdom than science.

What is Happiness?

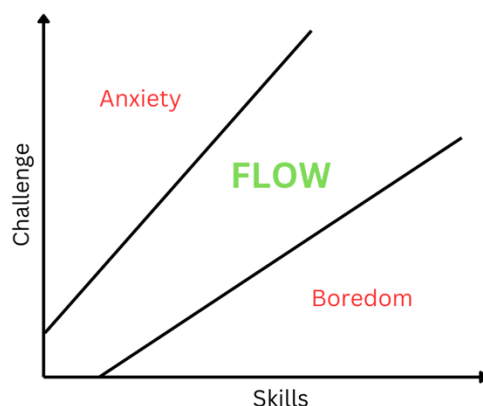
A long time ago, I was asked to do a talk on “stress management”. My reaction was: “Why manage stress? Chronic stress is bad for you!” It seems to me we have an anxiogenic society where even a vacation trip to the beach can be turned into a tsunami of worry if you let it. Why not have a happy life? Is there an evidence-based approach to happiness?” As it turns out, most psych research has focused on mental illness as opposed to wellness. Nevertheless, **while it tends to be relatively weak in terms of methodological rigor, there is more and more research piling up on what makes people happier.** One of the immediate problems with this research is how to define happiness and how it is different from joy, pleasure, life-satisfaction, general well-being, etc. Another big question at the population level is what to do with antidepressant usage. If a nation ranks highly for both happiness and antidepressants, does that count as a happy society or as an adequately treated unhappy society? Leaving these philosophical conundrums behind, I’ll just try to highlight some of the key findings on what seems to make people happier.



Aligne, Andrew, personal photograph by Rachael Aligne, with permission.

Flow

One of the key concepts that pops up over and over again in the happiness literature is **Flow: the idea, in both work and play, of having a balance between your challenges and skills.** You can increase your challenges as your skills increase over time. But you don’t want your challenges too high, or you’ll get burned out; and you don’t want them too low because



you’ll be unfulfilled. The trick is to stay in the zone in between. You need some control over your schedule to do that. In international studies, the people with the most Flow were farmworkers in the Alps.

I found this very interesting and made a detour to the Austrian Alps some years back when visiting family in Europe. The people who still do farm work there live in a beautiful natural environment, spend time with cows, horses and other domestic animals, walk up and down mountains a lot, and the change of seasons provides them a constant, gradual

variation in conditions. I can see how this would be a good set-up for living in flow, and it did seem that the people there valued these old ways of life.

PERSONAL FLOW ANECDOTE

In the photo at the top of this chapter, my wife is smiling after making it to the top of a mountain. As it turns out, in Austria they have chalets with yummy food and drink at the end of hikes, so you can hang out in style while enjoying the gorgeous view. The climb up was much harder for us than for the average local. Six-year-old girls were passing us. For us, it was NOT a good match of skills to challenge. It was a big achievement for us. It remains a good memory. There was great happiness in the moment at having reached our goal after a difficult struggle. But this kind of short-term high is like the relief from not banging your head against the wall anymore. It's not the same as being content in your life day-to-day. **Being in the Flow zone is less dramatic. But it seems like it's the way to be happy and healthy and helpful long-term.** To the extent that you can choose your life-conditions, you may want to think about finding this Goldilocks zone for yourself.

Setting things up so that more people can find flow more often appears to be the way to build a happy society. Basic life milestones should be possible challenges that most people achieve. In articles for Americans, **individuals from the countries that rank happiest in the world tend to explain to us that they are not obsessed with the individualistic rat race to always have more stuff.** They strive to have comfortable living standards for everyone.

This Flow concept has been life-changing for numerous readers. It helped them to question the notion that misery is a virtue. Burnout is not good for you or those around you. If your work situation keeps bouncing you around from one arduous assignment to another so that you never feel that you have mastery or control, then you are unlikely to be happy. **That is not about you!** That is a design feature of the system you are in. That is a problem with your environment. (Remember the Epidemiologic Triangle and Social Determinants of Health, etc.?)

As a leader or manager, it's good to think of Flow with respect to the people on your team. Someone could be working very hard but not getting anywhere because of a mismatch between challenges and skills. **The last person up the mountain may have worked way harder to get there than the one who got their first.** Helping others to find Flow is a great way to spread happiness around you.

One of the things that happens in Flow is the feeling that time stretches. Since you are right where you want to be in terms of mastering your task, you can accomplish it smoothly. You don't waste effort. You don't need to rush. And it turns out that **the feeling of "time affluence" is a predictor of well-being.**

Buying happiness

In our consumer-oriented culture, the question that often comes up is how to spend money to increase happiness. The general impression I get from the happiness literature is that people are not very good at predicting what will make them happy. The suggestions I have seen for shopping your way to happiness, indicate that you may want to prioritize: increasing your free time, supporting a hobby with Flow, facilitating pleasant experiences with friends and neighbors, making loved ones happy, giving generously, preserving pleasant memories, etc.

I hope the information in this chapter helps you and yours. If you think it's wrong and have something more solid to share on general happiness, please let me know.

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- Aligné, Andrew, personal photograph, with permission.
- Shin, Grace. Flow graph, 2024, with permission. Based on Csikszentmihalyi, Mihaly. 1990. *Flow: The Psychology of Optimal Experience*. United States: Harper Perennial.

Acknowledgments

Everything we do at the Hoekelman Center is improved by feedback from our stakeholders. If you have corrections or suggestions about this field guide, please let us know. Over the years, this text has been improved by the comments of many people, including hundreds of residents, students, faculty, and CBO partners. Thank you to all of them.

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Cover illustration by Dr. Terace Thomas

About the Hoekelman Center

www.hoekelmancenter.org

Dr. Robert Hoekelman was Chairman of the Department of Pediatrics at the University of Rochester, and a national leader in pediatric education. In particular, he was an early champion of moving physician training beyond the walls of the academic medical center. He was also a major advocate for primary care as well as what he called “pre-primary care”—otherwise known as community health action. He was a dedicated mentor, generous supporter and joyous participant of Rochester’s community pediatrics training program, which was named the Hoekelman Center in his honor shortly before his death in 2013.

The Hoekelman Center grew out of the PLC (Pediatric Links with the Community) program, founded by Drs. Jeffrey Kaczorowski, Laura Jean Shipley and Michelle Jones.

The Hoekelman Center is part of the University of Rochester School of Medicine’s Department of Pediatrics and Golisano Children’s Hospital.

Hoekelman Center Faculty & Staff 2024

Andy Aligne, MD, MPH; Sarah Collins-McGowan, MD; Marc Lavender, MD; Andy Sherman, MD, MPH; Susan Gasparino, MD; Rosa Lloyd, MBA; Kelly McDermott, MA (helped edit this version); Madelyn Rice (helped edit this version); Grace Shin (helped edit this version); Minhtam Tran (contributed graphics); Jessica VanScott, MPH (contributed a case study on the LARC Initiative); Diane Larter, MPA; Cheyenne Hall, MPH.

An accompanying instructor’s guide is in the works. It explains the philosophy of what we do and how we teach, and includes assorted group learning activities.

Solving many of our biggest health problems requires a vision of disease causation broader than the bio-medical model. With historical vignettes, illustrations, humor, links to resources, and case studies, this brief volume will help guide readers to an appreciation of the Epidemiologic Triangle and the public health paradigm. We know a lot about how to improve community health but there is a huge gap between what we know and what we do.

Bridging that gap depends on developing skills for implementing effective, evidence-based community health action locally and globally. Topics in this guide include: addressing social determinants of health; partnering with community organizations; predicting health impact of interventions; self-awareness of the culture of medicine; project design and management; evaluation on a shoestring; public speaking, talking to the media and other communications; legislative advocacy and “changing the world” in an hour a month; sustainability beyond grant-writing; behavior change.

The curriculum in this field guide has been replicated at sites across the US and the resultant community-based projects have won multiple national awards. This material has been taught successfully to health professionals from Pediatrics, Preventive Medicine, Family Medicine, Internal Medicine, and Psychology.

Andy Aligne is Director of the Hoekelman Center for Health Beyond Medicine in the Department of Pediatrics at the University of Rochester School of Medicine, Rochester, New York.



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