Chapter One

ENDING RACIAL, ETHNIC, AND CULTURAL DISPARITIES IN AMERICAN HEALTH CARE

Minority patients in America are more likely to wait entire weeks to begin treatment for breast cancer.[33]

Delays in treatment definitely increase the death rate for those minority patients.[34] The screening rates for breast cancer, colorectal cancer, and cervical cancer are also significantly lower for our minority populations.[35] Lower screening rates also increase the death rate -- because late stage cancers are much more difficult to cure than early stage cancers.

Minority patients are also significantly less likely to be diagnosed for depression -- and when minority patients are diagnosed with depression, those patients are significantly less likely to be treated for their depression.[36]

Minority patients whose kidneys fail are significantly less likely than white patients to have been under the care of a kidney specialist prior to the failure of their kidneys.[37]

Black patients are not only significantly less likely to have had specialist care before their kidneys failed, Black patients are also more likely to develop end-stage renal disease (ESRD) than white patients.[38]

Black patients are 1.3 times more likely to have a stroke -- and 3 to 6 times more likely to die from their stroke.[39]

According to the National Health Care Quality Report 2012 -- released in 2013 by the Agency for Healthcare Research and Quality -- health care outcomes, care quality, and access to care are all falling below our national goals in a number of key areas for our entire population.[40] To make matters worse, patient access and success levels for basic treatment in too many areas of basic care are actually lower for minority patients than for white patients in America. The rate of hospital admissions for uncontrolled diabetes, for example, is significantly higher for both Black and Hispanic patients -- compared to white patients -- and the death rate is higher for those patients.[41]

Research has also shown that both Black and Hispanic patients who have heart attacks are less likely than white patients to have received timely treatments[42] and are significantly less likely to have received a painkiller early in the care process.[43] Several studies have shown significantly lower and slower support for pain control for both Hispanic and Black patients. For basic care access, a number of studies have shown that Black and Hispanic patients are less

likely to receive coronary artery bypass surgery -- half as likely in one study -- for minority patients whose care needs were a good fit for that surgery.[44]

Multiple studies have shown us that access to health care resources and health care processes is not the same for all patient groups across this country and that Hispanic and Black patients tend to have reduced access to a number of care procedures.

Black, Asian, and Hispanic patients are all also significantly less likely to have a "usual primary care provider" than white patients.[45]

That is a very expensive care shortcoming.

Most care costs and care issues in this country today result from chronic disease. Care outcomes for most chronic diseases tend to be improved when patients have both a primary care provider and easy access to their care team. Both easy access and a "usual" primary care provider were less likely to happen for our Hispanic, Black, and Asian patients.[46]

Diabetes is a problem for all of our ethnic groups. It is now the fastest growing disease in America. The rate of diabetes is higher for our Hispanic and Black populations, and it is much higher for our American Indian populations.[47] Our Alaskan natives are 2.3 times as likely as white adults to be diagnosed with diabetes.[48]

In recent years, African Americans have accounted for a major percentage of the new HIV/AIDS diagnosis. Black patients and Hispanic patients both tend to have a death rate from that disease that is 50 percent or more higher than the death rate for white patients with that disease in most care settings.[49]

Hispanic women have an incidence rate for cancers of the cervix that is 1.38 times the rate for white women, and those patients also have a death rate that is 1.32 times higher than the death rate for white patients with the same disease.[50]

The health problems of our Native American populations are so significant that those issues deserve their own book.

Overall, there are a significant number of examples of care outcomes and care process disparities and differences that are becoming increasingly obvious to the people who are keeping track of the health status of our populations. Data about those care differences is obviously important information to have.

It is clear that we should be taking a long and clear look at our care delivery processes and approaches so we can figure out how we can deliver the right level of care to all patients, regardless of their race, gender, or ethnicity.

There Are Differences and There Are Disparities

When we look at the broad array of available data about comparative care outcomes and care processes, it is clear that there are some significant differences in outcomes and approaches that need to be both understood and responded to by us as a nation if we are truly concerned about the wellbeing of all of our citizens. There are obvious differences in several areas of care. We need to understand why those differences exist. We also need to understand what we should be doing about each of the differences. Where measureable differences exist, we need to look very directly at each of those differences and we need to understand what the relevant factors are for each difference. The differences we see among patient groups are not identical from disease to disease and they are clearly not identical from group to group.

Biology, Behavior and Bias All Create Care Differences

The differences -- when we study them closely -- obviously have a variety of causes. Three causes, biology, behavior, and bias -- tend to have the most impact. Biology, behavior and bias all create differences in care delivery and care outcomes. We need to understand which of those differences we see among groups of patients relate to differences in behavior, which relate to differences in biology, and which relate to actual disparities in care delivery, disparities in care access, or are the result of deficient and biased approaches to delivering needed care. All of those causes for care delivery differences exist. We need to know which set of causes are relevant to each disease and each health condition so that we can address each cause in the most effective way.

Bias is clearly a factor we need to understand more clearly and address very directly when it is a cause for the differences in care. Clearly, bias results in a number of care delivery differences that are not based on the medical science and best practices for individual patients.

Behavior Differences Are Important to Understand

Behavior differences are also extremely important differences to understand.

Variations in behavior cause variations in disease risk and disease development. There are several categories of behavior differences.

We very much need to understand which of the differences in care or care delivery are linked to behavior. We clearly need to know when any of the relevant behaviors that cause

differences in care outcomes or processes are caregiver behaviors. We also need to know when the behaviors that cause differences in care delivery or care outcomes are patient behaviors.

The answers are not as simple as one might think when first looking at the issue. When Black men who are having a heart attack are half as likely to be given a pain reliever early in the care process,[51] that set of data about caregiver behaviors can indicate the existence of either intentional or unintentional bias causing disparities in care delivery. For that set of differences in care, the behaviors that are relevant to creating the problem are the behaviors of the caregivers whose biased decisions about care create those care disparities.

Disparities Are Inappropriate, Unfair and Bad

Disparities, in that sense, are behavioral differences in care delivery that are inappropriate, unfair, and either intentionally or unintentionally biased against a given set of patients. Disparities are bad. Disparities reflect choices that are made -- for one reason or another -- against the self-interest and the best interest of a given set of patients. Denying vaccines to minority patients would be a behavioral disparity. Not testing minority patients for diabetes in order to avoid having to diagnose and treat diabetes for those patients would also be a disparity.

Being less likely to get a pain reliever or a medical procedure for a particular medical condition based on your race or your ethnicity group falls under the heading of care bias disparity. Medication differences of that sort are not a care difference. They are a care disparity.

But the fact that we know that Black women are roughly 70 percent more likely to become diabetic[52] is less the result of care delivery disparities than it is the basic reflection of both biological and behavioral differences for the groups of patients involved. In those instances, we need to address the behavioral differences of the patients -- not the caregivers -- and we also need to reflect and respect the higher levels of biological risk of each group of patients for those diseases in our disease detection, prevention, and treatment programs.

Patients Behaviors and Care System Behaviors

Behaviors cause some diseases. Other diseases are caused by biology. Black women are 47 percent more likely to get multiple sclerosis (MS).[53] We know that to be true.

If there are any behavioral underpinnings of any kind that might be triggering the higher level of MS that happens for Black women, those causes or those triggers that might increase risk levels for those women for MS are not known. Those differences in the MS rate -- with

Black women much more likely to get the disease -- are probably entirely biological instead of behavioral. But for diabetes, the situation is obviously much more complicated. We know for a fact that certain ethnic and racial groups are much more likely to become diabetic than other ethnic and racial groups. There are clearly biological risk factors. But we also know that the biological factors are heavily influenced by patient behaviors. We know that the behaviors of people in each of the higher risk groups can change the risk levels for people in those groups significantly. Diabetes is a great example. We know that individual people in the high-risk groups for that disease can increase the likelihood of personally getting that disease significantly by being physically inert and by being significantly overweight. Behavior is highly relevant for both of those issues. Weight and activity levels are both behavior-based differences that change the risk status for individual people. We know that when people have higher activity levels and when people weigh less, the risk of diabetes drops -- by more than half.[54]

Behaviors Trigger Diabetes

Behaviors clearly trigger diabetes. We know that to be true. The science is pretty clear. Both unhealthy eating and unhealthy inactivity trigger that disease. Both of those factors are extremely important. Most people don't understand how important basic activity levels are to diabetes prevention. As noted in the introduction to this book, the correlation between inactivity and diabetes is incredibly strong. A person who walks thirty minutes a day, five days a week is half as likely to become diabetic as a person who does not walk at all or who rarely walks.[55] A person who is inert is much more likely to become diabetic. That is true, regardless of the person's weight. Thin people who are completely inert can actually have a higher chronic disease level than overweight people who walk regularly.[56] Fit beats fat as a risk factor. Both activity and obesity increase the risk of becoming diabetic, however, and you can reduce the number of people who become diabetic with behavior changes that cause people to be consistently active and weigh less.

That set of factors has to be understood in light of the obvious differences in risk for diabetics that exist for different ethnic and racial groups. We obviously need to help our minority populations improve both activity levels and healthy eating levels if we want to stop the epidemic of diabetes from hurting even more people.

That knowledge base about the impact of those behaviors is part of the patient-focused, culturally competent solution set we need to discover, develop and enhance -- so we can deal most effectively with the difference levels that exist for diabetic care for each group of people. We also need to improve our skill sets and knowledge base so we can also significantly reduce the actual care gaps that exist between the various groups for patients who do have diabetes.

Care delivery disparities exist, and they obviously add another level of complexity to the issue. We know that African Americans who have advanced diabetes and kidney failure are, on average, significantly less likely to have seen a kidney specialist before their kidneys failed.[57]

Seeing those specialists in a timely manner can actually lead to better care. That better care can help keep a patient's kidneys from failing. A group of people whose kidneys failed because they did not have access to those specialists can fall under the category of care disparity.

But having kidneys fail because the diabetic patient is obese and inert falls more under the category of patient behavior-induced care outcomes rather than outcomes that are being caused by disparities or by bias in care access or care delivery. We will not succeed in our goals of better diabetic outcomes if we focus only on the part of the problem that is caused by care disparities. We need to focus on the overall, targeted outcomes we want for those patients, and then we need to deal with all of the relevant factors -- including biology and behaviors -- as a total package of issues rather than being focused ideologically, functionally, or politically on a subset of the package.

We Can Reduce Care Costs by Making Care Better

For us all to be as healthy as we each can be, we need a combination of personal behaviors that can help each of us reduce known risk. We also very much know that we need best care to help cure or minimize the damage that we each suffer when we do have diseases and then need to have those diseases treated. We need to hold the care system to a high level of expected and consistent performance when we each need care.

We need fewer kidneys to fail and we need fewer congestive heart failure patients and asthma patients in the emergency room. We obviously need to coach patients to take the steps needed to reduce the risks of their own health care problems, and we need to help caregivers deliver the right care when health care problems exist.

If we do that entire package well, we can reduce health care costs in the United States by making care better. Many people do not know that result can and should happen. Most of the time, for most medical conditions, better care actually costs less. One percent of the people in this country create 20 percent of all health care costs. Five percent of the population creates nearly 50 percent of all costs.[58] We all know that care costs are not spread evenly across the entire population. We all know that it is much less expensive to prevent a kidney failure than it is to do a kidney transplant. The kidney failure that requires a transplant puts people into that 1-percent high cost category that consumes so many of our health care dollars. It is much better to do interventions with several categories of patients to help keep those patients out of that 1-percent category. It is particularly important to do those interventions for our minority patients who the reports all show are much more likely to have their kidneys fail and then die from that disease.

We need to look at real cost numbers as we build our plans to improve care in America for all groups of people. As noted earlier, roughly 70 percent of the costs of care in this country relate to chronic conditions -- like diabetes, asthma, and congestive heart failure.[59] The burden

of those diseases also all tend to fall more heavily on our minority patient populations. That burden is exacerbated for many of our minority patients by the fact that the current lack of care delivery resources that are available for many of our minority patients makes early intervention for far too many of those patients relative to those key diseases much less likely to happen. So we have disparities in the availability of care resources for groups of people.

Insurance Disparities Exist as Well

We also face some significant intergroup disparities relative to health insurance today.

Health insurance disparities clearly exist.

The current lack of health insurance for far too many minority Americans is a significant disparity in its own right. As we look at areas where we can differentiate disparities from differences, health insurance has long been an area of significant -- and functionally relevant -- disparity. Over half of the uninsured people in this country today are minority.[60] In some very diverse states -- like California -- over 75 percent of the uninsured people are minority.[61] There is a clear and functional relationship between being insured and getting needed care for many patients. Not having insurance coverage to pay for care creates significant disparities for some people relative to having access to care -- particularly access to the levels of primary care where both early interventions and provider coached, patient-focused, patient-targeted behavior changes can significantly reduce the burden of those diseases for specific patients and groups of patients.

The Health Reform Law Is Intended to Reduce Insurance Disparities

That particular historical disparity relative to a high percentage of American minorities being uninsured will be significantly alleviated for many people at the beginning of next year. Those disparities will shrink for many people on January 1 because the new Affordable Care Act has an aggressive and extensive program that will extend coverage to many of our poorest Americans.

Medicaid will be significantly expanded in many settings. Those Medicaid expansions will help a lot with the current disparities problem in those states that decide to expand Medicaid. Our current national Medicaid program covers many of our poorest citizens now -- but Medicaid is not a comprehensive program today for all poor Americans.

People of color are disproportionately likely to continue to face coverage gaps due to state decisions not to expand Medicaid. In states that do not expand Medicaid, poor, uninsured adults will not gain a new coverage option and likely remain uninsured. People of color make up

the majority of uninsured individuals with incomes below the Medicaid expansion limit in states that are not moving forward with the expansion at this time.[62] Moreover, nearly half of all uninsured people of color with incomes below the Medicaid expansion limit reside in states that are not currently moving forward with the expansion.[63] Disparities in coverage and care are likely to persist in states that do not expand Medicaid due to continued coverage gaps.

The new Medicaid program that will begin next year in most states will cover all citizens who are just above and below the official federal poverty level. It isn't entirely clear yet how many states will expand their Medicaid programs at this point. The current coverage disparities issue will not be significantly reduced in those states that do not expand Medicaid. In most of the states where the planned Medicaid expansion will happen, however, the majority of the newly enrolled Medicaid-eligible people will be minority patients, and that will directly reduce the insurance coverage disparity trends.

The New Insurance Exchanges Will Benefit Low Income People as Well

As noted above, not all states will expand Medicaid. All states will, however, put in place new health insurance "exchange" markets for individual insurance coverage. Those new "exchanges" will provide access to subsidized coverage for low income people in all states. In some states, the new subsidized insurance market will supplement the expanded Medicaid programs. In other states, Medicaid will not expand, and the new exchanges will be the only program that helps reduce the current coverage disparity gaps. All states will have the new exchanges in place, however, and the exchanges will all provide subsidies for lower income people who decide to buy private health insurance through the exchanges. Those exchanges will be a very different way of buying individual health insurance.

The new insurance exchanges will offer competing private health plans as choices to all Americans who want to directly buy health insurance. In the past, people who wanted to buy individual insurance coverage in this country almost always needed to pass a health screen that was set up by each of the health insurance companies. The new law eliminates those health screens for the purchase of individual health insurance. There will be no health screens used by insurers in the new exchanges. Everyone in this country who wants to buy individual health insurance will now be able to buy that insurance, regardless of their current or past health status. The disparity issues that exist today for health insurance coverage will be helped significantly by the new exchanges because low income people who decide to buy their own health insurance through their local exchange will receive a subsidy from the government to make their premiums more affordable. A slight majority of the low income uninsured people who will have an opportunity to buy that subsidized insurance in most states will be from our minority populations.

The Premium Subsidies for Lower Income People Will Be Significant

The premium subsidies available in the exchanges will be significant. They will pay most of the premiums for the lowest income people who buy coverage in the exchange. That subsidy approach will, of course, make premiums much more affordable for many low income people.

That process and that program are not yet in place. The exchanges are being built, however, for January 1 effective dates. When they are in place, some of the current disparities that exist in insurance coverage by race and ethnicity should be reduced.

It's not known yet how many low income people will enroll in the exchanges. The actual number of people who will be eligible for the expanded Medicaid coverage also isn't entirely clear yet -- but the numbers in both programs will be significant, and that new coverage agenda clearly should help narrow the gap and reduce the number of people who will face the disparity of being uninsured.

Guaranteed Access to Insurance Does Not Create Guaranteed Access to Care

Those two insurance coverage expansion programs will not deal in any way with roughly 10 million currently uninsured people who are undocumented non-citizens.[64] But the newly subsidized insurance coverage and the major new Medicaid expansion could make a significant reduction in the number of uninsured citizens. Minority enrollment in those programs will help people get guaranteed access to insurance coverage -- but not, necessarily, guaranteed access to actual health care.

Access to Coverage Doesn't Create Access to Care

Access to actual care will not be guaranteed by the fact that people have become insured. Access to coverage does not guarantee access to care. The newly insured people will still need to find care sites and caregivers. In a number of areas, the number of care sites that will be available to the newly insured people may well be inadequate.

So ending coverage disparities would not end care disparities -- but reducing those disparities in insurance will significantly give the country a much better chance of eliminating disparities in care.

Some Care Gaps Are Widening

That set of circumstances and those changes in who will be insured next year in America obviously raises an interesting and important set of questions for us all -- in addition to creating some important opportunities. We need to take advantage of the opportunities to help end disparities in care. Disparities will continue to exist. So will differences in care delivery and health status. The data that shows significant differences in care levels, disease burdens and care outcomes between various racial and ethnic groups is both clear and compelling. Those differences and disparities truly exist, and they will continue to exist. As noted earlier, The National Health Care Quality Report for 2012 -- released this year -- said that the care gaps between some of the groups in some key areas of care delivery are widening rather than narrowing.[65]

If some care gaps are widening -- and if we really do believe as a nation that we should have a health care strategy, infrastructure, and an overall collective commitment to having the right care for each segment of our population -- then we need to look to see what strategies we can put in place to help us meet our overall goals of better care for all Americans.

The truth is we can't just make isolated changes in some areas of care delivery and hope to either reduce care disparities or improve care.

We need to make some significant changes in the way we deliver care to fully achieve those goals.

We Need Better Systems, Approaches, and Tools

This is actually a very good time for us to make some meaningful changes in the way we deliver care. That very powerful and well-researched IOM report that was written in 2003 about the issues we face as a country relative to care disparities said at that point in time that we need to make some significant changes in the systems, approaches, and tools we use to support care in order to create real improvement relative to many areas of care disparities.[66] The experts who created that 2003 report said we need better data, we need data by ethnic groups, we need data about a wider range of care delivery functions and areas, and we need better care support tools. They said we needed medical best practices, and we need those best practices consistently applied across all groups. The authors of that pioneering and insightful 2003 report were entirely correct. We do need some better tools, and we very much need significantly better and timelier data to deal effectively with most care disparities and most care improvement issues. Fortunately, we are currently in a time of great change and innovation for care delivery, and it is possible now -- for the first time in the history of care delivery -- to make

some real changes that can make care better, more accessible, more affordable, and even more equitable for the patients of this country. This is a good time to improve care.

The Science and Practice of Care Is Getting Better

The science of care is actually getting continuously better. The tool kits that are being used to support care delivery are getting much better. Electronic medical records, remote monitoring tools, and new electronic connectivity tools are all offering us new ways of thinking about care delivery that were not available to us just a few years ago. Electronic medical records are now giving us much better data about both individual patient care and about effective population care. We now can keep track of both patients and populations of patients in much more effective ways. We are currently poised at the edge of a possible revolution in both care connectivity and care improvement.

This is a very exciting time for care delivery -- and the good news for the issue of care disparities is that the entire new array of tools and services can and should be used to help us deal more effectively with the issues that we now face relative to both care disparities and care differences in American health care. Progress in all of those areas is now possible in ways that real progress functionality could not happen back in 2003 when that particular report was written. Those authors were ahead of their time -- but their dream can be actualized today. That isn't a hypothetical, speculative, or wishfully optimistic statement about the possibility of care improvement today. That statement about the possibility of real progress today is a belief that is based on some real-world, site-specific applications of several of those tools over the past couple of years in ways that have helped caregivers accomplish those exact goals and do it in a systematic, process-supported care environment.

The people who wrote that very powerful report said that care delivery would need better data, information flows that could be delineated to identify and focus on performance differences by race and ethnicity, and a higher dependence on medical best practices with best practices consistently applied for all people and all groups of patients. Those thinkers were entirely correct. That approach does work. The good news today is that we now have a real-world experiment that involves 9 million very diverse people who are being served today with the basic care support tool kits that were envisioned in the 2003 report.

That diverse population is the 9 million people who are now served by the Kaiser Permanente care system.[67] As the introduction to this book pointed out, that care system has

made an explicit and direct commitment to ending disparities in care delivery for the 9 million people it serves, and it is using some of the very tools that were described and recommended by the 2003 IOM report on health care disparities to do that work.

Kaiser Permanente has done some learning about those tools over the past several years. One learning is that it isn't enough to simply put the tools in place and hope that care gets better. Electronic medical records on their own and by themselves cure nothing. They aren't magic. They are tools.

Those tools need to be used, and they need to be used well -- but when that happens, disparities can be reduced, and the care differences that still exist can be care differences that are appropriate to the patient and functionally represent best care.

That targeted disparity-reduction work that has been done over the past several years at Kaiser Permanente needs to be better understood. That is the purpose of the next portion of this book.

Care disparities and differences exist in the U.S. We all know that to be true. People die every day because those disparities happen. It should be unacceptable to us as a nation to continue to have those huge differences in care outcomes -- and a four-year difference in the lifespan of people based on their race or ethnic group should not be acceptable to us as a country.

We need to look at the ways we can improve care for everyone and at the ways we can reduce disparities in care delivery and key outcomes. Care gaps should not happen.