

Racial and Ethnic Minority Health Disparities in Kansas

A Data and Chartbook



April 2005

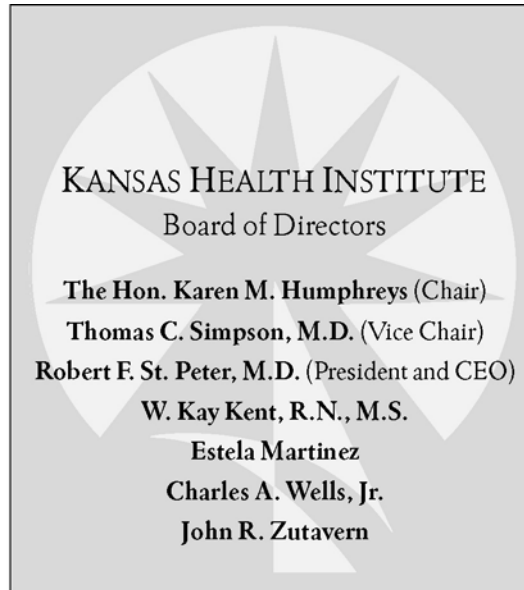
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The Kansas Health Institute is an independent, nonprofit health policy and research organization based in Topeka, Kansas.

Established in 1995 with a multi-year grant from the Kansas Health Foundation, the Kansas Health Institute conducts research and policy analysis on issues that affect the health of Kansans.

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MESSAGE FROM THE GOVERNOR

Almost without exception, the voices of racial and ethnic minorities are muffled in our overarching discussions of health care. Yet these groups almost always must meet distinct and difficult health care challenges. The publication of *Racial and Ethnic Minority Health Disparities in Kansas: A Data and Chartbook* thus provides cause for both celebration and concern.

We celebrate the investigation of racial and ethnic health disparities by the Kansas Turning Point project with a grant from the Kansas Department of Health and Environment, and the presentation of these important issues in their full social, behavioral, public health and health care contexts. We can also celebrate the hard work underway in many of our communities to ensure that every Kansan has an equal chance to lead a healthy life.

Still, the disparities noted here are shocking, especially in a nation where one dollar in every six goes to pay for health care. We must work together to improve the health of all Kansans, and especially those who systematically receive the least care.

For reforms to work well, we need the best information possible. This report represents one valuable step in a long journey, but it will inform the efforts of all who seek high-quality health care for Kansans of all races and ethnicities.

Kathleen Sebelius

Governor of the State of Kansas

FOREWORD

For years, our efforts to address disparities in health status affecting minority Kansans have been hampered by the absence of a summary resource. In 2000, the Kansas Department of Health and Environment asked the Kansas Health Institute to lead an effort to address that deficiency. The Robert Wood Johnson Foundation, through the Kansas Turning Point project, and the Kansas Health Foundation generously provided the financial support for this effort.

Racial and Ethnic Minority Health Disparities in Kansas: A Data and Chartbook and the shorter, companion flipbook titled *Minority Health Disparities in Kansas* are a set of data tools for population-oriented responses to health disparities at the state and local levels. They are foundation documents of **assessment**, making more accessible important data about minority health status and pinpointing critical gaps in such data. They are crucial building blocks for **assurance**, providing guidance to opportunities for institution and improvement of services; they are also invaluable sources for baseline data to evaluate the impact of efforts to reduce health disparities. Finally, all engaged in **health policy development** and **health advocacy** efforts should derive great benefit from the existence of this reliable and scientifically rigorous compilation of minority health data that have been assembled from a wide array of sources.

These documents make it clear that there are still many gaps in what we know about the health status of minority Kansans. It is important that we undertake to close those gaps. Such efforts must be built on collaboration with the minority communities of Kansas. The support and involvement of minority communities is essential in order to develop the ability to collect the data that are needed to understand the health needs of minority Kansans and effectively respond to those needs.

The Department of Health and Environment is pleased to have been able to bring this project to a successful outcome, and I am sure that, in partnership with many communities, these materials will be used to help improve the health of our state.

Howard Rodenberg, M.D., M.P.H.
Director, Division of Health
April 2005

ACKNOWLEDGMENTS

Wading into the complex issues of health disparities is filled with challenges that test your perspectives and world view. Throughout this project, the research team tried to remain objective and provide a data and chartbook that would express the authentic voices and perspectives of the Kansas communities experiencing disparities. These communities will judge whether the project team has succeeded in capturing the key issues they feel are important. We sincerely hope they approve of our effort.

The research team would like to thank all those who participated in the Kansas Turning Point project that was supported by grants from the Robert Wood Johnson Foundation and the Kansas Health Foundation. First, our deepest thanks to those who generously donated their time and shared their perspectives through both structured interviews and focus groups conducted across the state. Without your voices and input, this project could not have been completed. In particular, the communities of Garden City, Wichita, and Kansas City shared their resources and wisdom over many months.

Many individuals helped make the project a reality at the Kansas Health Institute, EnVisage Consulting, the Kansas Department of Health and Environment, Division of Health, the University of Kansas School of Medicine – Kansas City, the University of Kansas School of Medicine – Wichita, United Methodist Mexican-American Ministries (Garden City), the Center for Health and Wellness (Wichita), and the Native American Cancer Awareness Council (Kansas City). Each of these organizations has tremendously talented and dedicated staff who shared their work, their ideas and their encouragement throughout the project.

The authors would especially like to thank Michael J. Moser, M.D., FAAP, former Kansas Health Officer, who provided encouragement to the team and supported the use of a participatory research approach. This research process, while not typically used in public health studies, provided the opportunity to understand disparities through the values and experiences of those within our communities who are most familiar with them, and with the underlying causes of disparity and health inequity. Dr. Moser's trust in the research team and the collaboration

between KDHE and KHI which he fostered was a source of strength that allowed the project to take on the shape it needed.

Kim S. Kimminau, Ph.D., led the research team that conducted this study at the Kansas Health Institute, and she is responsible for the content. Interpretations of the data and opinions expressed are solely those of the authors and do not necessarily reflect the opinions of the Kansas Department of Health and Environment, the Kansas Health Institute, funding agencies or other partners involved in the project.

The authors regret including any mistakes or factual errors, and they take full responsibility for them. We know that the support from an excellent production team (Pam Clay, Cathy McNorton, Emily Lubliner and Marc Velasco) as well as the talent of our editors, Jan Sokoloff Harness and Ken DeSieghardt, greatly reduced our “error rate.” Challenging ideas – confronting difficult issues and closely examining the sources of disparities in Kansas – are included, and the authors take pride in that accomplishment.

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“From the minute of my birth – no, from the minute of my conception – I was disadvantaged and trying to catch up and I didn’t even know it.”
– African American participant in the Kansas Turning Point project

EXECUTIVE SUMMARY

Racial and ethnic minorities in Kansas are disadvantaged. The data reveal pervasive disparities in healthcare, in education, in employment, in housing – the interwoven list goes on and on.

The Kansas Turning Point project, funded by the Robert Wood Johnson Foundation and the Kansas Health Foundation, provided an opportunity for discussions of minority health and disparities with community residents and leaders across the state. We heard from African Americans in Wichita, concerned about diabetic relatives with no health insurance. We talked with Asians and Latinos in Garden City about the challenges of communicating with health professionals who only speak English. We listened as Native Americans in Kansas City expressed their personal hopelessness and their despair over children turning to alcohol and drugs.

The data collected by KHI and others reveal that each minority group in Kansas has a unique profile of health and disease. Our state results resemble national findings on racial and ethnic health disparities, and identify distinct problems that must be addressed, including:

- Kansas Native Americans die sooner than others from diabetes and report higher rates of risk behaviors that lead to injury and death
- Kansas African Americans have higher infant mortality, die sooner than others from cancer and diabetes, and often die from avoidable causes, such as homicide
- Kansas Asians and Pacific Islanders may be reluctant to submit to certain health screening tests and are, therefore, at risk for late detection of some diseases
- Kansas Latinos have the lowest rate of seeking early prenatal care and have the lowest educational attainment rates, a known predictor for poor health outcomes later in life

The problems of minority health disparities in Kansas are an echo of what is happening nationally. Although there have been initiatives throughout federal agencies and in many states, and support from national philanthropies, little improvement has been detected over the past 10 years since minority health disparities became a focus of attention.

One goal for the *Racial and Ethnic Minority Health Disparities in Kansas: A Data and Chartbook* was to organize data for use by communities seeking local change. Many times, the community leaders we spoke with lamented their inability to access available data on populations of color in their areas. They wanted to fully understand their community's health needs, rather than operate from stereotypes and assumptions.

A second goal was to identify issues that affect our ability to measure and monitor health disparities across the state for policymakers. As important as the data are, it's also important that many data are missing. For example, we do not know the major causes of hospitalization for Native Americans, Asians or Pacific Islanders, or the cancer statistics for Hispanics/Latinos. If our state wants to ensure the health of all citizens, these missing data make the job for public health, medical and social services much tougher. How can we be surprised that disparities exist when we cannot accomplish the prerequisite monitoring necessary to serve the health of the public effectively?

As alarming as these disparities are, they can be addressed. The prescription is action:

1. Encourage better and more consistent data
2. Monitor health conditions
3. Develop minority-targeted health programs
4. Improve the workforce
5. Establish an office of minority health
6. Build accountability
7. Support communities

Why take action now? Kansas has a window of opportunity to establish minority health as a priority, knowing that our population demographics will continue to change dramatically. Why take action at all? Certainly, there are health system financial benefits for eliminating disparities, but the need for action goes far beyond that. Disparity is a quality-of-life issue. No matter what our race or ethnicity, disparities impact our schools, our jobs, our neighbors and our communities. Minority health needs speak out in this report. It is time for all of us to give it the attention it deserves.

“We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.” – T.S. Eliot

INTRODUCTION

Disparities. Unequal treatment. Inequality. Discrimination. Conscious bias that may extend all the way to prejudice. These words from the Institute of Medicine’s (IOM) 2002 seminal work, *“Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare”* (Smedley, Stith, & Nelson, 2002) describe what we currently know and is documented related to differences in health among racial and ethnic groups. This book, published while we were conducting the Kansas Turning Point Minority Health Disparities project, provides a comprehensive view of disparities relevant to healthcare delivery at the national level. The principle findings from this and many other published works since then include the following:

1. Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.
2. Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and there is evidence of persistent racial and ethnic discrimination in many sectors of American life.
3. Many sources – including health systems, healthcare providers, patients and utilization managers – may contribute to racial and ethnic disparities in healthcare.
4. Bias, stereotyping, prejudice and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.
5. A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.

These key findings are presented in a comprehensive summary, but they only address *healthcare* disparities; a discussion of these disparities, along with others identified during the course of the Kansas Turning Point project, will be included as we examine why race and ethnicity have a role in health.

The *National Healthcare Disparities Report* (NHDR) (Agency for Healthcare Research and Quality, 2003) was released in 2003. The objective of the report was to help policymakers and researchers discern the areas of greatest need regarding health disparities, monitor trends over time, and identify successful programs for addressing those needs. It is different from the IOM report in that *Unequal Treatment* extensively documents healthcare disparities, while the NHDR examines the breadth of the problem from a national perspective. NHDR includes analysis of disparities, with particular attention to the impact of socioeconomic position, race and ethnicity on health. Importantly, the report provides baseline findings for use in measuring the effectiveness of national disparities reduction initiatives over time.

The findings of the NHDR reinforce the findings in the IOM report. Seven key points were identified to improve health services for all populations:

1. Inequity in quality persists
2. Disparities come at a personal and societal price
3. Differential access may lead to disparities in quality
4. Opportunities to provide preventive care are frequently missed
5. Knowledge of why disparities exist is limited
6. Improvement is possible
7. Data limitations hinder targeted improvement efforts

The NHDR report demonstrated that “racial, ethnic and socioeconomic disparities are national problems that affect healthcare at all points in the process, at all sites of care, and for all medical conditions – disparities are pervasive in our healthcare system” (Agency for Healthcare Research and Quality, 2003, p. 5).

Racial and Ethnic Minority Health Disparities in Kansas: A Data and Chartbook is modeled in the spirit of the NHDR. The hope of the Kansas Turning Point project is to provide a comprehensive baseline of measures relevant to state improvement initiatives. This *Data and Chartbook* is organized into two principal sections. The first section covers a variety of topics including the history of race and ethnicity in health statistics, a summary of national data sources on existing disparities, and community perspectives on the causes and effects of health disparities. Health characteristics of each major minority population in Kansas are included, along with a focus on disparities by major disease conditions. Key issues of causality, including socioeconomic factors, access to health services, quality issues and geographic factors, are then followed by a section on policy implications and recommendations. This section of the material was authored by Kim S. Kimminau, Ph.D., the principal investigator for this project.

Appendices in the second section present the data gathered throughout the project. Eight separate appendices provide both summary data-at-a-glance findings as well as data at the state, population density, and/or county level when available. Topics include demographics, housing, crime, education and health behaviors. This section of the *Data and Chartbook* was organized and written under the direction of Dr. Kimminau by Connie J. Satzler, M.S., and her staff at EnVisage Consulting, with contributions by Barbara J. LaClair, Cheng-Chung Huang and Jeff Alvarez of the Kansas Health Institute.

An additional Appendix section, “Minority Health Community Training Materials” includes presentations shared during the community data training activities, an additional phase of the Turning Point project. The authors of documents in this section are identified on each presentation title slide and include Kim Kimminau, Charlie Hunt, Henri Menager, Connie Satzler, Angelia Paschal and Barbara Starrett.

A glossary of terms, technical notes on how the team handled the data and reported them, a listing of web-based resources on minority health and disparities, and a selected bibliography complete the components of the *Data and Chartbook*.

KANSAS TURNING POINT INITIATIVE

The Turning Point Initiative was created by the Robert Wood Johnson Foundation (RWJF) and the W.K. Kellogg Foundation (WKKF) in 1994, with an initial group of 14 state-level grantees funded by RWJF and 41 community-level grantees funded by WKKF. The purpose of the Turning Point Initiative was to:

1. Sponsor and create an environment where state agencies and organizations and their community partners could plan collaboratively to analyze the issues and challenges related to public health systems improvements and link those to health status improvement.
2. Develop a strategic planning document that would communicate the state of the public health system and identify ways to address gaps in system capacity.
3. Highlight strategies that will sustain a public health workforce and improve information systems.
4. Establish a network of public health partners who would contribute to an agenda that addresses issues of public health importance such as eliminating disparities, increasing access to care, preventing infectious disease, reducing chronic disease and protecting the public from hazards and toxins in the environment (Berkowitz & Thompson, 2000).

Kansas was a state grant recipient in 1998. The initial funding focused on supporting statewide activities and the collaborative “Governor’s Public Health Improvement Commission.” The first-phase outcome of Turning Point was the production of a thorough assessment and a summary document highlighting gaps in a broad set of areas relevant to public health and public health infrastructure. Minority health was identified as a gap area. Participants in the Governor’s Public Health Improvement Commission process recognized that insufficient data on health disparities created a probable barrier for public health improvement for the state overall and specifically for racial and ethnic minority communities.

Additional support through the Turning Point Initiative and by the Kansas Health Foundation spurred the development of the Minority Health Disparities project represented by this *Data and Chartbook*. The goals of the Minority Health Disparities Turning Point project were to:

1. **Collect** and organize available health and other data relevant to minority populations in the state.
2. **Engage** community partners in identifying their concerns and areas of need in providing public health services to their minority communities.
3. **Inform** the development of state-specific Healthy People 2010 goals.

An additional component of the Turning Point project was expanded during the grant period. It included a community data training project, designed to help community members who work with minority Kansans understand public health concepts, how to use available data, and how to display and communicate information about their programs and services. These materials are included as a separate Appendix (Appendix I).

The Kansas Turning Point project turned to communities across the state in an effort to better understand whether and how nationally identified patterns of disparities were playing out at the state and local levels. **While Kansas' population continues to be characterized by a white majority, the state's racial and ethnic populations have both a long history and a growing presence in virtually every county.** Given that, do racial and ethnic minorities in Kansas share the disparities in health status, access to healthcare, and other health issues that have been documented nationally? Or, are Kansans different? If disparities in health do exist here, how do they compare to national patterns?

To address these questions, race and ethnicity data had to be gathered and evaluated so that an evidence-based assessment could be made. No single source of information had been developed to evaluate disparities at the state level, so the Turning Point project was identified as a critical component for the state to move forward on the issue. The cornerstone of the project is this *Data and Chartbook* that, for the first time, integrates the available information for communities, leaders and policymakers in the state. This project provides one place to access data relevant to ethnic and racial minorities in the state, and serves as a tool for community planning and data interpretation. Finally, the project included a goal of identifying gaps in the data available on minority health.

PARTICIPATORY RESEARCH

A participatory research approach was used for the health disparities project. Participatory research is defined as “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change” (Frankish, George, Daniel, Doyle Waters, & Walker, 1997). A principle tenet of this model is that the most authentic and realistic picture of any issue relevant to communities is best identified through a collaborative, community-focused process. If communities – and those ultimately impacted by the product of research – help shape the research, the resulting knowledge must be more relevant than if it was conducted without their influence and voice. In addition, the product of knowledge gained through community research should be put directly back into the hands of those who generated it. **Meaningful action and change can grow out of the process, because communities are intimately linked to the results and believe in their veracity, and elements of the system that are ready to change can take action with the inherent support of those who will be affected.**

Participatory research is not value-free. Our ways of making interpretations (including doing research) always are influenced by our social and cultural systems; these elements are an inescapable fact of our social nature, and our research is mediated to a large extent by our personal history and tradition, and by the culture of our times, by what we see and read. Participatory researchers are not only aware of this phenomenon, they are convinced that validating or challenging research findings is best accomplished by collaborating *with* those with whom they are doing the research. The difference is fundamental – participatory research requires collaboration and a collective discovery process. Communities are not studied *per se*, but rather are collaborators in the investigatory process.

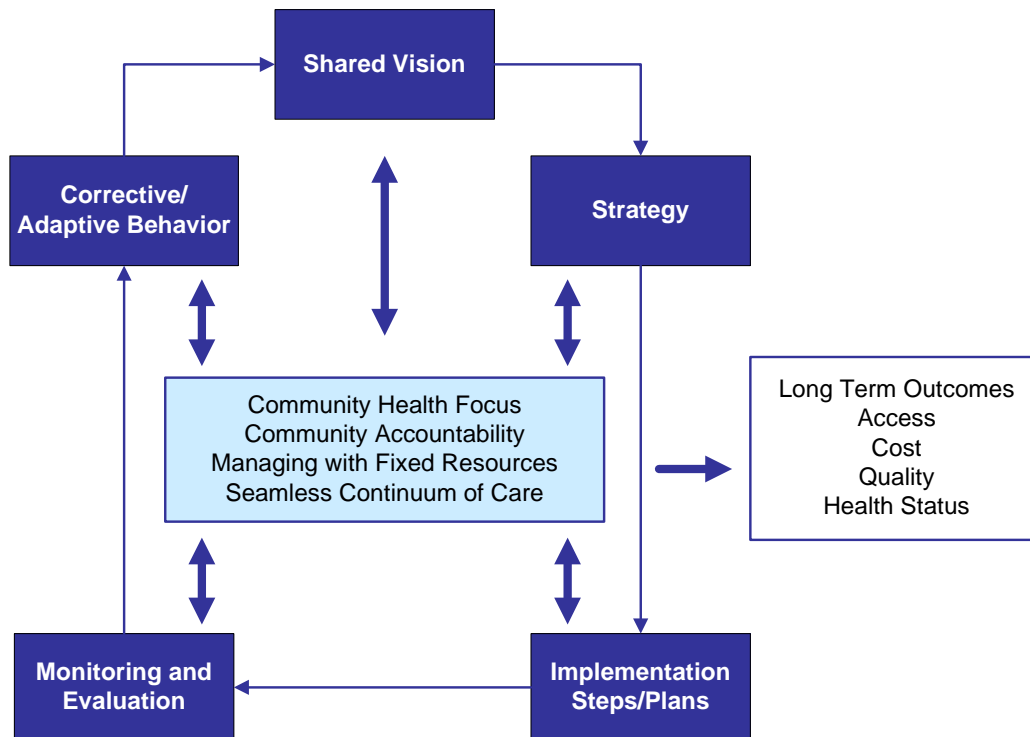
Participatory research has grown out of recognition that unequal relationships relative to knowledge perpetuate divisiveness. Inequality in access to information, the tools to understand data, and in the development of research data itself alienates the elite “researchers” and their research “subjects.” These very terms, researcher and subject, exemplify the unequal power position inherent in research. “Truth” is not the privilege of trained experts. Decisions based on “expert” knowledge that affect ordinary people deny the rationality of individual citizens and

their life experiences (Sohng, 1995). Specialists tend to dominate the debate concerning issues of public interest, because ordinary people are unable to enter the “scientized” debate: They lack the technical terminology and specialized language needed (Habermas, 1979).

This project brings the input of communities forward in the discussion of health disparities. Summaries of their comments and concerns are included along with the peer-reviewed literature. **Community impressions gained during interviews, focus groups and through other ethnographic approaches are shared in the hope that these perspectives will connect the realities of minority Kansans with the *data* of minority Kansans.** The project team believes participatory research can build alliances among those who will make choices, shape action and create change. We have much to gain by critically engaging the theory and practice of participatory research as we face the challenge of health disparities.

A community-based model for health improvement was used throughout the project, and is represented in Figure 1. Central to the model is that communities “drive” the process of long-term outcomes and health improvement. The Kansas Turning Point project approach to communities was to listen to their interests and concerns, attempt to understand their shared vision, and then assess the role of health data in helping them achieve their goals.

Figure 1. Community-Based Model for Health Improvement



Source: *Public-Private Partnerships to Improve Health Care*. Health Research and Educational Trust. <http://www.hret.org/hret/programs/content/CCNevalreport.pdf>

DEFINITION OF HEALTH AND SOCIAL DETERMINANTS

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization, 1946). This definition has not been revised since 1948, when the World Health Organization defined health by including the *positive* aspects of health. It is interesting that no revision has occurred, given the tremendous change in human genomics, greater understanding of the etiology of disease, and the broader adoption of the fundamental role of social factors in influencing health.

For this report, defining health from the communities’ perspective frequently included a broad range of issues that some would consider “non-health” related dimensions. Focus group participants cited adequate employment, a working wage, supportive family (specifically living near relatives), being a member of a vibrant religious community, and high-quality childcare and educational resources for children as contributing to health. Without these community features,

participants felt their health would be diminished or threatened, and that their children would be less likely to thrive. This finding was not prompted by the presentation of a social determinants approach to health. Rather, **communities identified, in very straightforward ways, their implicit understanding that health is a holistic concept involving social, emotional and spiritual health in addition to biological aspects of health.**

Throughout this project, we approached the topic of racial and ethnic disparities within the framework of a broad definition of health using a social determinants approach. Simply stated, “social determinants of health” means that lifestyles, and the conditions in which people work and live, are believed to have a strong influence on their health. These determinants have individual, social, economic, cultural, environmental and service factors. This field has emerged from the intersection between social and behavioral sciences, and medicine. An Internet search for the term “social determinants of health” reveals more than 300,000 websites or links, and there is a vast body of published literature on the subject.

While this research area has grown dramatically over the past 20 years, most studies remain largely descriptive, lacking both standards of scientific rigor and sophisticated measurement techniques present in other fields. These deficits result in many considering social determinants of health as an “emerging” field that has yet to identify quantitative contributions of various social and behavioral factors to health. Precisely because social and behavioral factors are so difficult to measure quantitatively, and because they are synergistic, teasing out their relative contributions to any measure of health is challenging. This relationship has been described as a complex system of reciprocal feedback loops, and the causal pathways crisscross disciplinary boundaries and loop back in positive and negative feedbacks. All in all, the measurement challenge to identify root causes exceeds the limits of epidemiology as we know it today. If measurement techniques were sophisticated enough to allow for modeling the impact of policy decisions, adopting effective interventions, and determining the kinds of investment needed to produce a positive health change, the effects would be enormous. This potential holds great promise for the future of social determinants. It is disappointing that at this point in time, many social determinants of health studies rest their findings and interpretations on descriptive

statistics and correlations, neither of which assist in understanding causality or the contributory impact of various factors on health outcomes.

Even with these shortcomings, studies that seek to understand the influence of socioeconomic status, access to healthcare and other resources, education, the effects of racism and segregation, and living and occupational conditions play a critical role in understanding disparities. **Communities across the state were somewhat aware of the evidence regarding medical treatment inequality; however, all of them recognized that disparities are perpetuated by fundamental social and behavioral factors.** Without addressing these root causes, the outcome of recognizing disparities among the various sources of data available will be of little long-term impact, in their view.

WHAT IS RACE?

BACKGROUND ON THE USE OF RACE AND ETHNICITY

The use of ethnic and racial categories has a long history, and is embedded in the earliest development of American health statistics. Race in particular has long had a federal role by being used for representational apportionment through the 1840s by the U.S. Census. As was typical of the time from the 1790s through the 1840s, races were typological, static and reflected political and social position more than anything remotely biological in nature (see Table 1).

Table 1. Select U.S. Census Categories, 1790-2000

| Year | Racial Categories |
|------|---|
| 1790 | Free White Males; White Females; All Other Persons; Slaves |
| 1820 | Free White Males; Free White Females; Free Colored Persons; All Other Persons except Indians Not Taxed; Slaves |
| 1840 | Free White Persons; Free Colored Persons; Slaves |
| 1880 | White; Black; Mulatto; Chinese; Indian |
| 1920 | White; Black; Mulatto; Indian; Chinese; Japanese; Filipino; Hindu; Korean; Other (plus write in) |
| 1960 | White; Negro; American Indian; Japanese; Chinese; Filipino; Hawaiian; Korean; Other (print race) |
| 1980 | White; Negro or Black; Japanese; Chinese; Filipino; Korean; Vietnamese; American Indian; Asian Indian; Hawaiian, Guamanian; Other Asian Pacific Islander; Other Race |
| 1990 | White; Black or Negro; American Indian; Eskimo; Aleut; Chinese; Filipino; Hawaiian; Korean; Vietnamese; Japanese; Asian Indian; Samoan; Guamanian; Other Asian Pacific Islander, Other |
| 2000 | White; Black, African American or Negro; American Indian or Alaska Native; Asian Indian, Chinese; Filipino; Japanese; Korean; Vietnamese; Native Hawaiian; Guamanian or Chamorro; Samoan; Other Asian; Other Pacific Islander; Some other race (print race) |

Racial theory advanced in the 1850s with the publication of Darwin’s *On the Origin of Species* and the development of the theory of natural selection to explain natural diversity. Social determinists quickly took up natural selection and gave rise to the notion of social races – those of higher class and standing were innately superior to those of lower socioeconomic class. This misuse of the notion of survival of the fittest, and the inappropriate application of “fitness” to social and economic success rather than success at leaving offspring, continues even today.

In a direct way, the U.S. Census and the census-taking process continued to build racial theory. The Census developed ways in which human variation, as reflected in phenotypically (observable) racial characteristics, would be classified and organized. This structure informed how these groupings would be used for a wide variety of datasets, including ones relevant to health. Racial taxonomies continually change under the influence of social, political and migration events, such as the 1880s' inclusion of "Chinese" or that of "Hawaiians" in 1960. From the 1930s through the 1960s, a number of pivotal changes occurred. The biological race concept was defeated among academics and replaced with recognition that biological variability is continuous. U.S. minority populations were on the rise; the nation was increasingly diverse, with larger numbers of immigrants. The civil rights movement emerged, and a growing national focus on social equality gained acceptance.

From the 1970s through the most recent census taken in 2000, racial categories again were changed. The federal Office of Management and Budget (OMB) governs the statistical reporting by all federal agencies with respect to race and ethnicity. In 1994, OMB formed the Interagency Committee for the Review of Racial and Ethnic Standards, and in 1977, OMB released Statistical Directive No. 15. This Directive established that "Hispanic" was an ethnic and not a racial category, and that in cases of self-identification, individuals should choose the category that "most closely reflects the individual's recognition in his community." For the first time in U.S. Census history, in 2000, respondents could choose more than one race on their census schedules, selecting from five racial groups and 15 categories. Furthermore, there was no single, multiracial category choice. The five principle categories include: White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander (see Table 2).

Throughout the text section of *Racial and Ethnic Minority Health Disparities in Kansas: A Data and Chartbook*, the terms black and African American are used interchangeably, as are the terms Hispanic and Latino. Throughout the text section, the term "white" refers to non-Hispanic whites. Throughout the appendices, the choice of racial and ethnic terms used reflects the terminology used in the *source* for the data presented. Finally, Asians, Native Hawaiians and Other Pacific Islanders are combined because of their small population size in the state.

Table 2. U.S. Census Categories, 2000

| Racial Category | Racial Grouping |
|----------------------------------|---|
| White | White |
| Black, African American | Black, African American |
| American Indian or Alaska Native | American Indian or Alaska Native |
| Asian Indian | Asian |
| Chinese | Asian |
| Filipino | Asian |
| Japanese | Asian |
| Korean | Asian |
| Vietnamese | Asian |
| Other Asian | Asian |
| Native Hawaiian | Native Hawaiian or Other Pacific Islander |
| Guamanian or Chamorro | Native Hawaiian or Other Pacific Islander |
| Samoan | Native Hawaiian or Other Pacific Islander |
| Other Pacific Islander | Native Hawaiian or Other Pacific Islander |
| Some Other Race (print race) | |

Source: Office of Management and Budget. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. Federal Register 1997;52(210). Available at <http://www.whitehouse.gov/omb/fedreg/ombdir15.html>.

Census categories historically have included a broad array of racial, population, religious, ethnic and geopolitical classifications, and been revised to reflect current needs (i.e., political, social, ethnic) for categorization. Quite simply, race has long been used as a social category and not a biological one.

Social dimensions of race are evident when each group is examined closely. African Americans, for example, come from many societies, including many from the African continent, and from the English-, French-, Dutch-, Portuguese-, and Spanish-speaking nations of the Americas and Caribbean. Because of their skin color, society tends to aggregate them into the African American category, even though their ethnicities may be very different. The same holds true of Hispanics/Latinos – many different cultures with unique beliefs, family structures,

medical models, dietary patterns and more – are bundled together with a single ethnicity designation.

Social and behavioral scientists have been active at both ends of the argument when it comes to race. The early development and application of taxonomic principles to human variation was championed by some in these disciplines, and later the charge to dismiss the use of race altogether as an explanatory factor was also accomplished by these individuals. While the biological basis for differences we observe clearly results from a set of biological processes, linking the genetic and phenotypic (observable) expressions of these traits to health is not entirely possible. Advances in human genetic research have already identified links between various genetic characteristics and certain illnesses or health conditions. However, the precise mapping of genetic-to-outcome linkage has yet to be widely established. This observation does not dismiss the need to understand the ways in which race has influenced population health; it could make such study even more important. Whether or not a particular racial or ethnic group has genetic or biological characteristics that predispose them to certain health risks, or whether their membership in a particular racial or ethnic group influences external factors that predispose them to the same risks becomes more of an argument of root cause and not relevant to dealing with the health outcome itself.

DISCRIMINATION AND RACISM

In light of historic forces that have disadvantaged groups of individuals based on either their ethnicity or on their race (skin color), or both, these same categorizations have been used to mitigate the effects through programs like affirmative action. Race and one of its consequences, racism, has led to calls for social justice that require the recognition of race, even in light of the evidence that it does not have a biological basis and that it is more a relevant social construct than a biological marker.

Racism is the belief that some races are superior to others, and the exercise of discrimination based on that belief (McNeilly Dominguez et al., 1996). One model for understanding the insidious impact of racial stereotyping and racism is provided by Camara Phyllis Jones. Jones argues that race precisely captures the social classification of people in our society, and she and

others suggest that race-associated differences in health are due to the effects of racism (Jones, 2000; Krieger, Rowley, Herman, Avery, & Phillips, 1993).

Institutionalized, personally mediated, and internalized racism form a triumvirate that grips our contemporary culture. Institutionalized racism forms the framework where differential access to core, high-quality resources – such as the best educational systems, neighborhoods, environments, and employment opportunities – are limited to those who have historically controlled political and social power. With institutionalized racism, systemic and pervasive impacts permeate or influence social, political and environmental dimensions of society.

Personally mediated racism represents those behaviors expressed on an individual-to-individual basis which display disrespect, prejudice or discrimination based on race. Personally mediated racism generally focuses on skin color, but it can be based on ethnicity – a person’s native language, culture, etc. This is the outward manifestation of ethnocentrism and a world view that permits individuals to treat others with a lack of respect and to devalue, dehumanize and be suspicious of those who are “different.” The general population is shocked when cases of personally mediated racism are revealed. The case of Susan Smith of Union, South Carolina, is one recent example that documents such racism. Smith, a white woman, was convicted of murdering her two sons by driving them into a lake and drowning them after she initially attempted to blame their deaths on a black man. She described a scene of being stopped at a red light, forced to drive off at gunpoint, being able to get out of the car three or four miles down the road and having the driver leave the scene with her 3-year-old and 14-month-old sons still inside. She described the driver as “a black male in his late 20s to 30s, wearing a plaid shirt, jeans and a toboggan-type hat” (Brooke, 1994). This is an example of scapegoating which fuels racism and uses stereotypes to blame others.

Internalized racism is defined as acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth (Jones, 2000). This results in accepting – most often unconsciously – lower expectations and a self-imposed disenfranchisement of privileges. People suffering from internal racism might fail to vote or drop out of school; this

type of racism creates a personal burden of resignation and helplessness.

Throughout the Turning Point project, participants told stories that highlighted internalized racism. For example, some Native American Kansans revealed their sense of hopelessness for a healthy life for themselves, but fervently hoped they could do something to “save the next generation”; they wanted to target the reduction of health disparities in their children to spare them the negative health outcomes from which they were suffering. This community also recognized the resilience of their spirits and will; even while carrying the burden of internalized racism, they were cognizant of their power to influence the next generation.

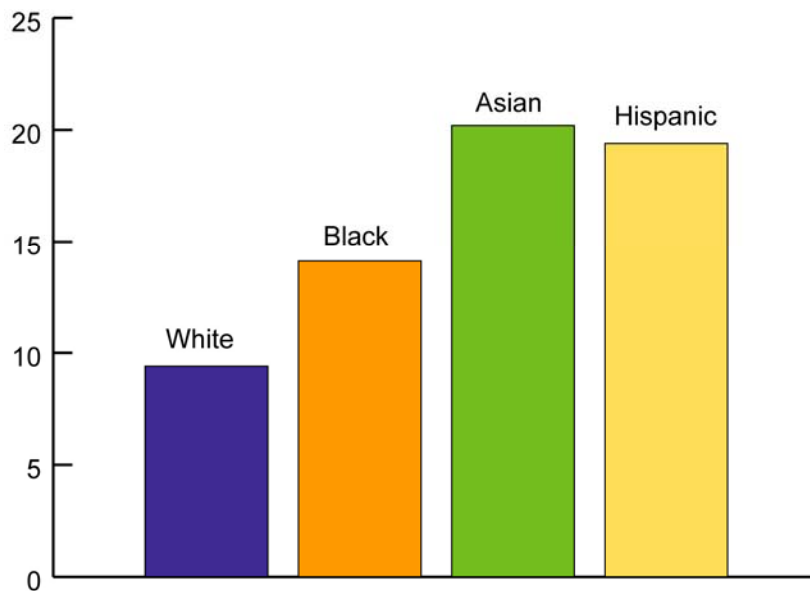
By whatever process, unconscious bias or through overt prejudice, the impact of race has a number of influencing effects on health. The Institute of Medicine’s report, *Unequal Treatment* finds that there is a range of patient-level, provider-level and system-level factors that may be directly involved in healthcare disparities. For example, patient-level factors included minorities refusing recommended services or adhering poorly to treatment regimens. Provider-level factors, such as providers not always treating patients with comparable conditions in the same way, leads to what the IOM report called “clinical encounter disparities.” System-level factors included language and cultural barriers between patients and sources of care. These, and other “care process-level variables” might be operating from the delivery side of medical care, and in each case, they are influenced by a set of social and historic constraints related to racial attitudes and behaviors.

A relatively new hypothesis regarding racism’s direct impact on health is that it contributes to stress. Stress produced because of racism can be expressed on an individual level (internalized feelings of low self-esteem or worth), community level (concentrations of racial populations in impoverished neighborhoods with inadequate housing or with exposure to environmental risks) and on a larger scale (unequal distribution of resources in society). In a study conducted among African American women, 50 percent reported being discriminated against some of the time in public (Vines et al., 2004). At least 83 percent reported that blacks are 1) watched more closely than other workers and have their work scrutinized more often; 2) hired at a lower grade or starting salary and 3) followed or watched more closely when shopping. Fifty-seven percent of

the more than 450 participants reported an experience with racism, and 26 percent described the experience as very stressful. At least 60 percent reported being very concerned about their children getting poor instruction in school, being harassed by police, getting stopped in white neighborhoods, being punished more harshly, being discouraged from trying things and having fewer choices. Racism's subtle and overt influence is likely expressed on a continuum, from modest impact to direct health factors, such as stress, that are associated with poor health and health outcomes.

Minorities are significantly more likely than whites to report being looked down upon or disrespected in patient-provider relationships (Figure 2) (Blanchard & Lurie, 2004). Researchers cite both race and language as reasons why minorities felt they were treated unfairly; minorities also felt they would have received better care had they belonged to another race. Men were more likely than women to report feeling disrespected by doctors. Those without a college education were more likely to believe they had been treated with disrespect. One important corollary to these findings is that **respondents who report negative experiences with providers were also less likely to get appropriate and necessary care. When care is delivered in an environment that seems unwelcoming or even hostile, avoidance is a natural response.** For health issues that require treatment, follow-up and monitoring, such avoidance may result in poorer outcomes.

Figure 2. Percent of Patients Who Felt They Were Looked Down Upon/Treated with Disrespect by Their Doctors



Source: J. Blanchard and N. Lurie (2004)

Recent studies document the persistence of discrimination, particularly for African Americans (Cose, 1993), but Hispanics and Asian Americans also experience it (Kim & Lewis, 1994; Telles & Murgia, 1990). The 1995 Detroit Area Study (DAS) assessed major experiences of discrimination without reference to ethnicity or race. This design component allowed for the separate assessment of racial discrimination from that based on other social factors. While a recent study documented a relatively low level of discrimination (11 percent of respondents reported that they or a family member had been treated badly because of race) (Williams & Chung, 1997), the DAS found that routine discourtesies – receiving poorer service than others in restaurants, being treated as if you’re not smart, being called names – may result in stress and have other psychosocial impacts. How individuals respond to discrimination and manage it is an area of little scientific investigation. Many, however, believe that the ways individuals handle such stressors have indirect and direct effects on their cardiovascular health and mental health, and that these accommodations vary by individual, by gender and by race.

These findings, and many others in the literature, document that **our society's standards regarding race have substantial impact on many aspects of our daily lives**. These impacts are expressed in many different forms, including some with a direct health cost and others that contribute to environmental conditions which have high, indirect costs on health.

RACE AND HEALTH

Researchers frequently use race as a variable in medical and health services research. This challenge has not stopped researchers from using a classificatory system that includes a discrete variable which is imprecise and largely biologically irrelevant. What results is a form of biological determinism built on the assumption that identified differences have a genetic origin. A contemporary rationale for the inclusion of race rests not as much on expecting race to identify underlying biological reasons for variation captured in a research study, but on using it as a proxy for relevant social, behavioral and perhaps biological factors that influence the condition under study. Often, race is included as an independent variable in a multivariate model of health. The hope is that it will explain, in a statistical sense, some level of the variance measured. In cases where race partially “explains” the pattern of relationships identified in the multivariate model, what does that tell the researcher? What should it tell all of us? The imprecision of what race actually represents – perhaps some set of predisposing behavioral conditions, perhaps something genetic or biologic – yields a particularly unsatisfying result. When race does explain part of the variance, we lack the ability to target interventions in any meaningful way. For example, what aspect of the racial experience could be modified to improve the opportunities of racial populations to achieve more positive health outcomes?

This line of discussion argues for the irrelevance of race in health services research. The use of race does, however, deserve attention. Most frequently, race is a classificatory tool that identifies individuals based on one dimension of expressed, biological variation – skin color. The important health factor is whether skin color influences how an individual or group is treated within the social and medical system. The definition of race is rarely made explicit by researchers, likely reflecting their reluctance to write about a subject they have little training in or feel is too volatile to discuss. Fear of offending sensibilities has pushed our society into not discussing race at all. The field of health services research will not move forward in providing

dynamic and multilevel explanations of health and disease causality until researchers disclose exactly what they mean by the classificatory systems of race they use.

Even when researchers statistically control for educational attainment and other socioeconomic factors, hypertension is frequently thought to have a significant genetic component for African Americans. The weakness of this argument is that it is fundamentally reductionistic: critical psychosocial aspects of lifelong experiences resulting from racial differences are not taken into account. Even though this weakness has been cogently presented (Cooper & Rotimi, 1994)), many articles continue to be written that link assumed genetic factors with the higher incidence of hypertension among African Americans.

When racial differences are observed, providing an interpretation of the finding is necessary, but rarely done. Race and ethnicity (shared behaviors due to common ancestry and social ties) may sometimes explain the pattern(s) within or between group differences. For example, dietary preferences typical in a particular region may account for obesity or cardiovascular disease risk. For example, the “Southern” diet may impact Southern African Americans differently than African Americans who live in the Northeast. Race expressed as biological variability/skin color may reflect opportunities or barriers experienced due to differential access to high-quality educational institutions. Education might be the underlying cause for differences correlated with health knowledge and disease prevention awareness.

Whatever the pathway, we must explain the nature of the influence of race on health. It is insufficient to use race as part of a multivariate model, reduce and explain some level of the variance within the model by race, and then not provide for a model or pathway by which race has had its influence.

ETHNICITY AND HEALTH

Ethnicity suffers the same fate as race as a concept in many health studies. Ethnicity is defined here as a set of traditions, behaviors, common history, social practices, religion or belief system, and other components of shared, group social behavior. Although not explicitly defined or delimited, characterizations of health risk sometimes are explained with the term “ethnicity.”

Many different groups are represented in the summary level category labeled Hispanic/Latino. Individuals may share a language (Spanish, Portuguese) or share ancestral ties to Spain or countries of Latin America. By the 1930 U.S. Census, a new category was added to the race/color question that gave formal acceptance to using Mexican nationality for race (Hayes-Bautista & Chapa, 2002). Within 10 years, the Census reversed itself and directed that Mexicans were to be listed as white unless they were Indian or of some other non-white racial group. The resulting confusion has led to individuals of different nationalities, languages, cultures and races being grouped together as Hispanic/Latino over time.

In the United States, “Hispanic” is the only currently recognized ethnicity at the federal level. The OMB Directive 15 recognized “Hispanic” as an ethnicity in 1977, and individuals now are directed to select their ethnicity as “Hispanic” or “Not Hispanic” in a separate U.S. Census question that does not refer to race.

Surnames, birthplace and the Spanish language have each been used to classify Latinos over the years. The lack of clarity has led to many different classifications – one person or group may be included or excluded, depending on which factors define the classification. Currently, the least objectionable term for these populations is “Latino,” collectively representing individuals who share a Latin American affiliation. The label “Hispanic” used throughout the appendices of this material maintains an association between the data and the label used in the data source, and it was the most common term applied in most cases. It is important to recognize that the use of “Latino” based primarily on nationality will “reshuffle” populations previously grouped together. For example, if the term is limited to those who were born in a Latin American country, it would include non-Hispanic Latin Americans such as Brazilians or Guyanese and would exclude Spanish, Portuguese, Cape Verdean and Filipino individuals. This is particularly important when attempting to compare health statistics over periods when the classification parameters changed.

A major challenge in understanding the impact of ethnicity on health is that the choices of race and ethnicity are not necessarily culturally relevant or understood at the individual or community levels. Frequently, both or at least one of these data fields are left incomplete.

Those who choose the ethnicity category “Hispanic” are most likely to leave the “Race” category blank, believing their definitions of race and their personal identity are best captured with the use of ethnicity alone.

However defined, Latinos are a vast and varied population. **There can be as much variability within the population labeled Latino as there is between Latinos and other ethnic or racial groups.** Many different indigenous populations, as well as various European groups, have had an impact on Latinos and Latino culture over time. Further, whether an Hispanic individual is foreign-born or U.S.-born likely has an impact on their health.

Parallel to the discussion of race, the use of ethnicity as a predictor or explanatory variable of a health condition is murky. In fact, the phenomenon called the “Hispanic paradox” demonstrates the pitfall of trying to understand an extremely diverse group and health outcomes. Latinos nationally are characterized by low income, low levels of educational attainment and high proportions of workers in blue-collar or unskilled occupations. However, their all-cause mortality and infant mortality rates are low – lower than would be expected by comparison with African Americans and other groups who share a similar set of socioeconomic characteristics. The lower all-cause mortality is thought to be related to relatively lower mortality among older Latinos for the diseases that are the leading causes of death for the majority of Americans such as cardiovascular disease, stroke and cancer (Franzini, Ribble, & Keddie, 2002)

There are a number of hypotheses concerning the cause of the Hispanic paradox. One is referred to as the “salmon bias hypothesis” which suggests that the paradox stems from elderly Hispanics returning to their native countries. This would remove them from national death records and statistics, thereby affecting the numerator used to calculate mortality rates. This hypothesis can only be supported for foreign-born individuals, and it was tested by examining Cubans who could not return to Cuba for political reasons and Puerto Ricans whose deaths would be recorded in U.S. vital statistics regardless of their return to Puerto Rico. These groups had lower mortality rates than non-Hispanic whites, providing evidence against the salmon bias hypothesis. This explanation is not well-supported with Kansas data, as Cubans and Puerto Ricans tend to perform better than other Hispanic groups on a number of maternal and child

health measures (i.e., prenatal care; see Appendix F-5). The difficulty in assessing the hypothesis in Kansas is largely due to the lack of older Hispanics in the state, making even age-adjusted mortality data unreliable.

Another hypothesis, called the “healthy migrant” hypothesis, is based on the idea that the healthiest members of a population are most likely to migrate to a new country. They may represent the healthiest individuals from their home country, but there would be no reason to suggest that Latino migrants would be any different in this regard than migrants from other nations. In fact, non-Hispanic white migrants do not seem to have the same mortality advantage as that of Hispanic migrants, suggesting that the healthy migrant hypothesis is not a major explanation for the Hispanic paradox (Abraido-Lanza, Dohrenwend, Ng-Mak, & Turner, 1999).

Other factors, such as acculturation and culture itself, may have strong mediating influences on risk factors and other aspects of social determinants of health that impact the Hispanic paradox. Less-acculturated Hispanics identify with their native culture and retain their foodways and other behaviors that contribute to a healthy lifestyle as compared to U.S.-born Latinos who grow up in an American culture. Once acculturation and the adaptation of diet and behavior swing towards a typical American lifestyle, a change in health profile occurs. A strong ethnic identity may have a protective health effect among Latinos, particularly among Mexican Americans, that is not seen among African Americans (James, 1993). If this is the case, the insulating affect of ethnic identity is only effective as long as their culture remains distinct from the majority American population.

Another dimension of ethnicity that has a direct impact on health is the use of complementary and alternative medicine, and healers. An estimated one in three Americans uses some type of complementary or alternative medicine for chronic illness, including herbal medicines, acupuncture and massage (Eisenberg et al., 1993). A number of studies indicate that perhaps 50 percent or more Hispanics, particularly elders, use some type of complementary medicine (Astin, Pelletier, Marie, & Haskell, 2000).

At least three systems of non-traditional healing are important to studies of Hispanics/Latinos in Kansas. *Curanderismo*, *espiritismo* and *santeria* are traditional systems of care for a variety of Latino cultures. Providers include Mexican folk healers (*curanderos*), Puerto Rican faith healers (*espiritistas*), Cuban faith healers (*santeros*), as well as herbalists (*yerbistas*) and massage therapists (*sobadores*), and you can find these practitioners across the state. It is unclear how many Latinos access these sources of care, but anecdotal examples – and the availability of necessary products, such as herbs seen in many markets and stores – attest to the use of these complementary services.

Small sample studies have documented that Mexican Americans in particular may choose traditional healing and remedies because of the high cost of prescription medicines (Applewhite-Lozano, 1995). It is important for medical providers to realize these individuals may be using herbal and other remedies in place of prescriptions. Unless providers are sensitive to the cultural practices among their clients and invite conversation about such behaviors, they will be treating their patients without knowing the possible effects of these interventions.

Figure 3. Folk Medicine



Kim Kimminau

“Remedios,” or remedies, are complimentary herbal medicines used in folk medicine. This photo was taken in a Hispanic grocery store in Garden City, Kansas.

“I care for riches, to make gifts
to friends, or lead a sick man back to health
with ease and plenty. Else small aid is wealth
for daily gladness; once a man be done
with hunger, rich and poor are all as one.” – Euripides

WHAT ARE DISPARITIES?

A review of the terms “disparity,” “inequality” and “inequity” reveals significant variation in their use and application to health. “Health disparity” is used most often in the United States, while “health inequality” more often is used internationally (Carter-Pokras & Baquet, 2002). “Disparity” usually describes a measurable difference in a health indicator, regardless of whether the cause(s) is inevitable, unfair or unjust. “Equity” exists when disparities are absent (Braveman & Gruskin, 2003). “Inequality” implies that a fundamental unfairness contributes to the difference between the groups being compared. Those who use the term “inequality” rarely define whether they think the cause(s) is unnecessary and amenable to intervention, or whether it is inevitable and unavoidable. The feature of preventability does not ascribe whether the group could modify the risk on its own, or whether public policy or civil society could marshal the resources to eliminate or mitigate the cause. Finally, “inequity” is generally reserved for those cases of disparity/inequality where health determinants *are* avoidable to some degree and are socially unacceptable. In all cases, the challenge is to identify with certainty which determinants of health underlie a given inequality and to quantify their contribution to the condition examined.

Margaret Whitehead argues that disparities arise from: 1) natural, biological variation 2) health-damaging behavior that is freely chosen, such as participation in certain sports or pastimes; 3) the transient health advantage of one group over another when one group is first to adopt a health-promoting behavior, as long as other groups have the means to catch up fairly soon; 4) health-damaging behavior in which the degree of lifestyle choices is severely restricted; 5) exposure to unhealthy, stressful living and working conditions; 6) inadequate access to essential health services and other basic services; 7) natural selection, or health-related social mobility involving the tendency for sick people to move down the social scale (Whitehead, 1991).

According to Whitehead, health disparities determined by the first three categories would not be considered unfair nor unjust, while the last four would be “considered by many to be avoidable and the resultant health differences to be unjust.”

Disparities are differences. Various organizations and researchers include differences in health status, adverse health conditions and death rates in their definitions; there is no unified approach, and this presents a problem. The units of comparison can change the finding of disparity. For example, Hispanics have a lower incidence rate of gonorrhea than the entire U.S. population, but have a higher rate than that of non-Hispanic whites (Carter-Pokras & Baquet, 2002). In the first case, there is no disparity. In the second, there is. Throughout this report’s appendices, data are presented for the reader’s comparison at the state level, at the level of population density of groups of counties, and at the level of the individual county, where possible. This is done so that a determination of disparity, based on the relevant comparative grouping, can be made.

Current interest in eliminating disparities began with the Clinton administration’s 1998 call to eliminate disparities in infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection/AIDS and immunizations. These health issues were selected because, at the time, they reflected areas known to affect multiple racial and ethnic groups at all life stages. The initial National Institutes of Health (NIH) definition of disparity was based on “differences in the incidence, prevalence, mortality and burden of diseases and other adverse health outcomes that exist among specific population groups in the United States” (National Institutes of Health (US), 2000). The specific populations of focus included African Americans, Asians, Pacific Islanders, Hispanics/Latinos, Native Americans and Native Alaskans, but an allowance to examine disparities related to socioeconomic status also was included.

What is missing from the NIH definition and what continues to be a challenge today is that this national initiative seeks solutions to health disparities without a clear framework or model on what *causes* them in the first place, what the appropriate units of comparison should be, and whether or not a difference identified is avoidable and therefore preventable. If disparities exist because of inequalities, which unequal condition is amenable to intervention and which is not?

Which health condition is caused by a determinant or set of determinants that can be modified with the goal of health improvement? **Simply identifying that a health condition is different between two population groups does not necessarily lead to clarity on what should be done to equalize or modify conditions so that the less-well-off population can achieve the same or comparable health outcome as the higher-performing/healthier population.**

Another important dimension is determining whether the cause of inequality is avoidable. For example, inequality based on age is largely unavoidable. Like it or not, as we age, biological changes occur that cannot be prevented. In contrast, if people are predisposed to health risks because of inequality in workplace conditions or early childhood education, those risks are avoidable and could theoretically be mitigated by appropriate policy intervention(s).

The role of ethical judgment in health disparities adds another layer of complexity. Ethical judgment enters the arena because decisions must be made on how to modify the risk for the benefit of health outcomes, and assessment of whether an inequity is present and unjust will direct the focus on which risk(s) to modify. The IOM report, *Unequal Access*, focuses on only one aspect of known health disparity – that of differences in medical treatment. The central question for that work was whether anything can be done to avoid the negative aspects of the underlying causes that lead to medical treatment differences. If policymakers and others want to improve the overall health of minorities, they must change conditions that lead to disparities in the first place.

KANSAS COMMUNITY PERSPECTIVES ON WHAT CAUSES HEALTH DISPARITIES

Examining the nature of health differences within and among various social, economic, racial and ethnic groups commonly recognized in the United States and in Kansas is complex. One way to unravel that complexity is to study disparities and the story of them in Kansas through the eyes of those who experience their impact. With this in mind, we asked those most directly affected by disparities what they think *causes* disparities, what forces encourage their persistence and what they feel can be done to eliminate them. Awareness within communities of racial and ethnic bias, health disparities, and challenges to maintaining personal, family and community health had not been assessed, and the project team was anxious to learn how communities

viewed the idea of health disparities and how they might be addressing the core issues that contribute to them. The use of a participatory research model allowed informants to guide where the project team focused, clarifying what data they felt would be most telling, most useful and most relevant to local efforts to improve the health of special populations in their community.

So, what do communities think the most important social and environmental factors are that contribute to disparities? What do they consider the social determinants of health? **Given no specific framework, community participants generally agreed on eight determinants that lead to health disparities: medical care, health behaviors, health insurance and income, working conditions, housing and community resources, early child development, education, and biology/genetics.**

Medical Care – Access, Cost, Quality

The provision of medical care has many dimensions. First, medical care has to be accessible to those who need it. Access may mean that there is a provider, clinic or hospital located nearby, but it also may mean whether or not someone can financially afford to seek services, let alone receive them. Once received, the quality of medical care – measured by adherence to best practices or clinical guidelines, acumen in differential diagnosis or performance of medical procedures with relatively greater skill – may vary among those providing care. It has been suggested that there may be a quality difference between providers practicing in more affluent areas and those “forced” to practice in less-affluent or less-desirable communities. The argument rests on the financial differences providers settle for if they practice in lower socioeconomic communities. Those who graduate higher in their class and have more prestigious residencies and specialty training can command higher fees, take on little or no charity care, and join or start practices in higher-quality neighborhoods. These individuals *may* provide better quality care than those who graduate towards the bottom of their class, who do not have the opportunity to select higher-income-generating specialties, and cannot afford to set up their practices because of debt and/or the cost of loan repayment – the providers more likely to practice in lower-income areas. If this hypothesis is supported, it reflects another dimension of the impact of neighborhood level differences based on socioeconomic factors observed among communities that participated in this study.

Another aspect of access barriers is that racial and ethnic minorities may not seek preventive or treatment services at times that result in the best possible outcomes. Why? If the number of accessible providers is limited, even the simple act of scheduling an appointment may be time-intensive and difficult. In addition, taking time off from work, arranging childcare and handling transportation barriers may make routine visits costly and challenging.

A key issue raised by minority communities in Kansas is their perception that the American health system is focused on treatment – not prevention. **Preventing disease in the first place by promoting social and living conditions that support healthy lifestyles has been neglected as a public health and policy issue, even though there is an accepted notion that this approach is cost-effective and more just than the current system of care.** If prevention is a key to promoting health (and thereby decreasing the need for health services either too early in an individual’s life or for avoidable conditions), then communities generally think that local services, tuned in to the many needs of local communities, are the most effective way to increase healthy outcomes. Communities across Kansas feel that local clinics, hospitals and health departments need to work collaboratively to encourage community health in its broadest sense.

Health Behaviors

A prominent social determinant hypothesis for health disparities is that the elevated risk among the socioeconomically disadvantaged is largely due to the higher prevalence of health risk behaviors among those with lower levels of education and income (Lantz et al., 1998). The association of risky behaviors, for example, binge drinking or not wearing seat belts, with poor health plays a role in health disparities, and some of these behavioral risk patterns are described in Appendix H. Communities interviewed had a clear sense of the role of personal responsibility, but they felt equally strongly that many “blame the victim” when it comes to holding minorities responsible for engaging in health risk behaviors. **They argue that the use of alcohol or tobacco, for example, is among a limited number of coping strategies that individuals use to deal with the stress of their disadvantaged position in society. Without condoning such behavior, many of those interviewed for this study feel that such addictions and behaviors are somewhat understandable when viewed in context.** They further suggest that simply controlling these kinds of behaviors is not likely to eliminate disparities. In fact Lantz et al. note

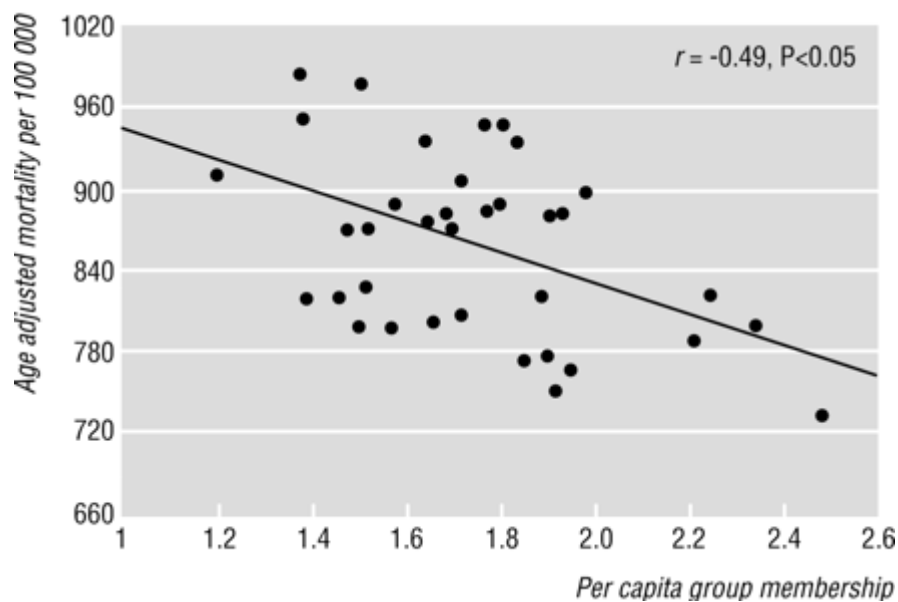
that socioeconomic differences in mortality will persist, even if risk behaviors decrease among the disadvantaged.

Health behaviors must be understood within the social and cultural context of racial and ethnic minority life. Food selection, preparation and consumption are excellent examples of how lifestyle, familial or cultural behaviors influence health. There is abundant evidence that acculturation to Western and American diet frequently results in health problems for recent immigrants (Delpapa & Mayer, 1990). Modifying traditional food patterns has a long history of impacting immigrant populations by shifting their diets and resulting in increased obesity, type 2 diabetes, hyperlipidemia and other conditions associated with chronic disease and poor health. At the same time, we frequently maintain our ethnic and cultural identities by holding on to traditional food patterns while also adopting new foodways. This complex phenomenon makes delivering messages about weight control and the health risks of weight gain very challenging to public health and healthcare professionals. Communities and individuals interviewed voiced concern that those delivering health messages be fully aware of the important sociocultural context in which health behavior modification is sought. For example, health messaging and social marketing may target a behavior with significant social, cultural or religious context, such as the traditional use of tobacco among Native Americans. If the context for the behavior is not well understood or respected, modifying that behavior is a challenge.

Health Insurance and Income

In these days of unprecedented economic growth, ill health disproportionately afflicts poor people worldwide (World Health Organization, 2002). In the United States, the poverty rate has remained relatively stable, along with the percentage of people without health insurance. Health insurance is influenced by employment, income and work conditions, and they all impact health. National data demonstrate that efforts to decrease poverty have been only slightly, if at all, effective (in 1990, 13 percent of the U.S. population was below poverty and in 2000, only a one percent improvement was measured). Health insurance, while of great interest and considered to be a major factor in predicting health outcomes and health status, also has shown very little change over the past 10 years.

Figure 4. Relation of Per Capita Group Membership in United States to Age Adjusted Total Mortality



Source: Kawachi and Kennedy, *BMJ* 1997;314:1037 (5 April)

Researchers have identified a gradient between income and health measures. One example is shared in Figure 4 by Kawachi and Kennedy (1997). Some researchers feel that inequitable income distribution, and the continuously widening gap between high- and low-wage workers (as well as between the employed and unemployed), is a fundamental characteristic of our social system that drives disparities (Daniels, Kennedy, & Kawachi, 2000; Kawachi & Kennedy, 1997). Communities in Kansas could not agree more. Insurance coverage unanimously was considered a prerequisite for receiving *any* healthcare, and there was a strong corollary that insurance coverage largely predicts the ability to receive *quality* care. Of particular concern is whether individuals are covered by public or private insurance, and the nature of the benefits themselves. Many of those who serve racial and ethnic minorities recognized that **individuals without the ability to pay do not seek care at all, or postpone treatment until a condition is urgent**. A single illness or accident can bankrupt a family, and charity care and safety net providers are not able to adequately meet all the needs arising from these situations.

Furthermore, communities recognize that being relegated to “second class” health is a consequence of not being able to compete for higher wage jobs that offer health insurance

benefits. Communities believe that inability stems from many factors including poor-quality primary and secondary education, limited opportunities to develop trade skills or matriculate into high-quality colleges and universities, and overall racial and ethnic bias encountered once in the workforce.

Of all of the underlying causes for health disparities, income and poverty – and their direct influence on health – garnered the most focus during discussions. **The influence of income was most frequently cited as the single most fundamental cause for differences in health and for disparities.** As groups agreed to the premise that income contributes to health, they focused more on the causes of income differences than on any specific health issue the research team would pose for discussion. For example, participants would discuss the disproportionate burden of certain cancers in their communities in the context of how a poor-quality education impacts earning potential and leaves people vulnerable to underinsurance. Further, they argue that individuals who must make a trade-off between out-of-pocket costs for care and other expenses – coupled with the humiliation of seeking services you cannot pay for – leads to their late diagnosis. Differential age-adjusted mortality statistics shared with these participants won knowing nods; none of the data demonstrating late diagnosis and worse outcomes including premature death surprised those working directly with racial and ethnic minorities across the state.

Lower-wage jobs may be insufficient to support individuals or families, and individuals may need to take on two or more jobs to meet their needs. Not only does this lifestyle bring with it the stress of balancing many priorities over the course of the day, it is unlikely to provide workers with opportunities for professional growth or advancement. While preoccupied with balancing multiple job responsibilities, study participants clearly identified the stress such lifestyles bring to other family members, particularly children. When parents increase work hours because hourly wages are low or because they need to take on more than one low-paying job, they are less available for their family. This conflict can lead to stress that affects the entire family in terms of spousal support, parenting and emotional stability.

Stories describing the stress of making conscious health choices based on financial factors were common. The theme of income and poverty was almost always at the forefront of the communities' views of either the cause of health disparity or the way in which communities could combat disparity. **This later theme of using education to combat disparities often was shared as the most hopeful way to end health disparities.** Many participants believed that the playing field for good health would be leveled if educational quality were equal for all. If everyone had an equal opportunity to attain educational success, there would be less of a competitive advantage allowing any one group to succeed at the expense of other groups.

Working Conditions

A job that exposes workers to industrial risks or hazardous materials, or work that requires repetitive movements or sustained immobility, carries a substantial health impact. These health risks occur disproportionately for the racial and ethnic minorities frequently employed in these positions. These jobs tend to be lower-wage positions, they may not offer health insurance benefits or the cost of insurance offered is too high. Again, with limited income, working conditions that force minorities to choose between health insurance and other expenses are considered by many to be unjust.

Undocumented (also known as “undeclared”) workers face additional challenges in the workplace. They do not qualify for federal assistance programs like Medicaid, they may face deportation if found to be working illegally, and they are likely employed in jobs that offer little or no health benefits, yet they continue to serve many roles in the Kansas economy. State health department programs serve many of these individuals, and the range of services they require are not unlike other uninsured or underinsured groups' needs in the state. The data collected through the Kansas farmworker program, for example, has an extensive case management database that tracks their services and also collects some health status information. However, knowing the full extent of this sub-population's needs is difficult to ascertain because they live and work without ways of counting their numbers or identifying them directly in other data sources.

Housing and Community Resources

Affordable housing is a critical aspect of being able to maintain individual and family stability. **It is estimated that more than 22 percent of Kansas' housing is inferior due to one or more physical or financial conditions, such as lack of plumbing facilities.** Among the 30 percent who rent homes, most are racial and ethnic minority Kansans. These homes are often in neighborhoods that may be exposed to noise, air and other pollutants, or may pose a risk to children by being located near high vehicular or railway traffic areas. In addition, these homes may be of older construction, where asbestos or lead-based paints were used. Both of these environmental hazards represent significant health risks.

Community resources that impact racial and ethnic minority families include many factors. Minority and poorer communities are more likely to live in polluted environments, and there may also be a disproportionate placement of pollution-intensive industries and hazardous waste sites in low-income and minority communities (National Institute of Environmental Health Sciences, 2005). Whether communities have sidewalks, lighted streets, an adequate supply of police, fire and emergency services personnel, locally owned businesses and supermarkets have all been associated with health. One example is the limited number of supermarkets or locations to buy fresh food, fruit and vegetables in northeast Wichita, an area characterized by a substantial African American population. When community resources are scarce, particularly those resources necessary for encouraging healthy behaviors, it comes as no surprise that the impact is felt on the health status of those communities.

In Kansas, one in 10 households reported food insecurity or hunger in a report conducted by KHI in 2004. National research among low-income families shows that mothers first sacrifice their own nutrition by restricting their food intake to protect their children. Food restriction has a health impact and, for pregnant women, may contribute to poor birth outcomes for their infants. Studies on the effect of undernutrition and malnutrition demonstrate that nutrient limitation has both short- and longer-term impact. Finally, studies indicate that older individuals who suffer from malnutrition have poorer health outcomes (Akner & Cederholm, 2001). An issue to address in this regard is that some communities of color lack

available markets and stores where they could purchase fresh produce and other high-quality foods.

Another key component of community is the presence of strong, faith-based organizations. There is a greater dependence on churches and their leaders within the African American and Latino communities compared to other racial groups. The typical black church has an average attendance about 50 percent greater than that of the typical white church; 63 percent say the pastors of black churches are the most important leaders in the African American community; and 91 percent of Hispanics say their faith is a very important part of their daily life (Barna Group, 2005). Latino and African American participants in this study expect to receive key health messages from the pulpit, and they consider the church a central player in community health improvement. Clergy activism on health issues is quite variable and largely a matter of their personal choice, so some community members feel the church is an asset in health improvement while others wish that were the case.

Early Childhood Development

Access to a positive early developmental environment is critical for infants and children. Informants in the project often said early disadvantages set the stage for persistent disparities later in life. As one African American participant stated, “From the minute of my birth – no, from the minute of my conception – I was disadvantaged and trying to catch up and I didn’t even know it.” Social dimensions of how parents nurture children and expose them to healthy lifestyles and health-promoting behaviors are influenced by a complex set of environmental, educational and behavioral interactions. While all parents likely hold the same hope for health for their children, expectations of health and access to care that can promote health in early childhood is not available to everyone equally. One component contributing to health disparities is the availability of affordable, quality childcare. It has been demonstrated that licensed quality childcare improves developmental and health outcomes of children in general, and children-at-risk in particular (Raphael, Bryant, & Curry-Stevens, 2004). Lack of access to such care is a challenge communities cite when discussing the disadvantaged environment of many racial and ethnic minority children.

Education

Education is a key determinant of health, and communities often refer to improved educational opportunities as key to reducing disparities. Educational attainment and positive health has been linked in many studies (Kitagawa & Hauser, 1973). For example, a relationship between socioeconomic indicators and risk factors for cardiovascular disease has been shown to be strongest and most consistent for education (Wickleby, Jatulis, Frank, & Fortmann, 1992). Many racial and ethnic minority students in the state fail to complete school (see Appendix C). The impact of this disparity not only seems to affect health outcomes, it also predicts socioeconomic differentials described in the Health Insurance and Income section above. Furthermore, even when educational levels are equal, opportunities for educational advancement may not apply to all students, particularly if the financial and emotional costs of continuing an education are too great. For individuals living below poverty thresholds, education seems to have little relation to health status, suggesting that substantial material deprivation cannot be buffered or mediated by educational factors (Krieger & Fee, 1994).

Participants in this study identified other issues when asked about the role of education in disparities. First, some participants suggested that appropriate accommodations for minority students are not always made by schools and teachers. Generally, they referenced the need for early remedial support for students entering school without key learning skills. There was a sense that when children do not receive services at critical points in their development, they tend to carry those deficiencies with them throughout their educational careers. There were some participants who felt that cultural and linguistic barriers were primary reasons why many ethnic and racial minority students struggled, and they suggested that one way to improve this condition was to train and recruit a more diverse educational workforce.

Another dimension of the education issue is one expressed by Asian participants in this study. Asians are often stereotyped as the “model minority.” A common mainstream understanding is that Asians are college-educated, particularly gifted in math and science, and do not need special accommodations in educational settings. This stereotype is particularly detrimental, because it casts *all* Asian and Pacific Islanders in one light, without recognition of the variable experiences within their population. For example, although nationally approximately

42 percent of all Asian American adults have a college degree, Vietnamese Americans have a college attainment rate of 16 percent, only one-quarter the rate for other Asian ethnic groups. The rates for Laotians, Cambodians and Khmer are even lower, around five percent (Le, 2001). Some have argued that this stereotype camouflages or excuses workplace discrimination whereby some qualified Asians and Pacific Islanders are overlooked for promotion and career development opportunities. This phenomenon, sometimes referred to as the “glass ceiling,” leaves qualified Asian Americans underemployed.

Many participants shared their concern that academic expectations were set too low for their children. They identified a perception that teachers may not expect as much from their children, and, by doing so, send a message to children that their lower level of performance was not only acceptable but was all they should strive to achieve or expect. The message these children get is that they are *expected* to perform poorly. Children can live up or down to expectations; when expectations are low, children are not motivated to perform to their highest potential.

Biology and Genetics

As reviewed earlier, there are two dominant historical perspectives on race and ethnicity. One perspective is rooted in the eugenics movement that treated racial and ethnic categories as biological classifications, or at least as groupings that reflect biological differences (Huxley, 1951; Kevles, 1995). The other tradition argued that race and ethnicity are primarily social and historic constructs with little biological significance (Boas, 1942). What remains, however, is the subtle presumption that racial and ethnic distinctions nonetheless capture “some” meaningful biological differences (Kaufman & Cooper, 2001). Both the empirical and conceptual relationships between social populations and biological features can be subtle (Juengst, 1998), and racial and ethnic communities believe there is something to these relationships.

Regardless of the largely academic confusion over whether racial categories are “real” and whether they reflect true underlying biological health risks, minority communities are likely to believe that they are, at least in part, at biological risk because of these categorical groupings. This notion is reinforced by their knowledge that diabetes, hypertension, certain cancers and

other diseases are more prevalent in their population than in the majority population. Feeling “fated” to suffer one of these illnesses is an undercurrent present in discussions of health risk. Some in the community believe there is a level of biological predisposition to such illnesses that has largely to do with their race. Sickle cell anemia among sub-Saharan African populations and their descendents, thalassemia in Middle Eastern, North African and Mediterranean populations and Tay-Sachs disease among Ashkenazi Jews all contribute to the idea that particular populations are more susceptible to certain (genetic) diseases than others, even though these conditions occur in other populations as well.

“We come from many countries, and we work hard, hard, hard. We all came here to find the American Dream.” – Vietnamese Businessman, Garden City

“Language is a big issue, but speaking Spanish doesn’t mean that we don’t deserve respect.” – Latina Health Provider, Garden City

KANSAS COMMUNITY PERSPECTIVES – GARDEN CITY

Garden City, Kansas, is a diverse, vibrant community characterized by many different ethnic populations. It has been called the most cosmopolitan city in Kansas. Finney County, where Garden City is located, is one of only 61 counties in the entire United States where more than 20 percent of the population was born in another country. Employment draws immigrants to southwestern Kansas, and meatpacking is the primary industry for immigrants and residents. In the 1980s, rapid economic growth was spurred by the establishment of one of the world’s largest packing plants, which attracted more than 6,000 new residents. The city had a longstanding Mexican American community, but with the opportunities presented by a large employer, Vietnamese, Lao, Cambodian and ethnic Chinese, as well as Latino populations from Central and South America, moved to Garden City. The Ford Foundation selected Garden City (along with Los Angeles, Miami, Chicago, Houston and Philadelphia) for a study led by Don Stull, Ph.D., of the University of Kansas with Michael Broadway, Ph.D., of Wichita State University, as the only non-urban city involving how newcomers and established residents adapt to one another.

The impact of these diverse populations has an effect on virtually every aspect of life in this community, from education to housing to health services. Schools are challenged to meet the needs of children who speak English as a second language. Affordable and available housing is a concern when any community’s population grows quickly. Grocers carry the diverse foods needed for various ethnic cooking, and restaurants, book stores and music vendors cater to many different languages and cultures. Multilingual services are essential for working with the diverse needs of the community, and cultural competency to deal with idiosyncratic or unique cultural approaches to health and wellness must be achieved. A high level of worker turnover, primarily due to the demands and pressures of the meatpacking industry, provides a stream of new workers to take their place, and that process inevitably affects community stability.

Given the geographic location of Garden City and its distance from centers of political power and influence in the state, Garden Citians tend to think of how they can solve their own problems, and health disparities is one area they recognize as critical to the vitality of the community. Garden Citians identify clear pathways to disparities in health for those in their community. The following list identifies the top 11 recurrent themes, issues and concerns that the Asian and Pacific Islander community and the Latino community feel are key to their health:

1. Many minority and immigrant families are living from paycheck to paycheck. Hourly workers in the meatpacking industry cannot depend on a stable 40-hour work week throughout the year. When companies slow production and only permit full-time workers 32 hours of paid work, family resources are strained. **Discretionary income is limited or non-existent, so if medical services have out-of-pocket costs, care is delayed or not sought.** This pattern presents a recurrent challenge for those delivering health services – particularly for those trying to encourage routine visits for conditions such as hypertension and diabetes.
2. The importance of family in Latino and Asian cultures is extremely high. The family is a critical source of strength and stability for these populations, and family values affect health decisions, particularly for children. For example, while many Hispanics/Latinos interviewed had little concern about cardiovascular disease or stroke (feeling that it was premature to be overly concerned personally, because these diseases affect the elderly), they were very concerned about immunizations for their children. **The health and well-being of their children was often the central focus of answers about crime, gangs, and neighborhood safety, as well as in discussions of elementary education.**
3. Prenatal care is not considered essential to a positive birth outcome, and Latinos interviewed were generally puzzled with Western medicine’s view of pregnancy as an illness requiring treatment. The cultures of many Latinos have a medical model that sees pregnancy as natural and in some cases, mystical, and interference in the process (even to provide preventive care or simply ongoing monitoring) is considered at best a waste of resources and, at worst, a possible source of negative influence on the health of the baby.

4. Garden City minorities considered education to be absolutely essential in providing for a positive future. Expanding multilingual and cross-cultural services within the school district was a common concern. Asians interviewed for this project cited educational opportunities as critical for their children, but many lamented the fact that when they or their parents came to the United States, they took jobs with less pay and prestige than those they had in their home countries. Breaking out of the cycle of underemployment, and being seen as leaders and senior managers, is a frustration for some.
5. A strong entrepreneurial spirit and a positive approach to business development and community growth were widespread. The community seemed to understand that health services in Garden City are strained to meet the need, but they also felt that a combination of faith-based services, public services and charity was serving the community well.
6. **Hardships shared appear to draw the community together.** The working conditions in cattle feed lots and meatpacking plants serve as a common experience understood by both the Asian and Hispanic/Latino communities, as well as within the white population. The general geographic isolation of Garden City contributed to this phenomenon, too. This common bond serves to support the perception by Garden Citians that they are the ones who best understand one another, and that outsiders tend to trivialize or only partially understand the lives they lead. They are equally proud of having many diverse businesses in their community, and while they recognize the labor that the meatpacking plants bring to their region, they point to the fact that they have a diverse local economy.
7. Lack of integration and cooperation among health services organizations was seen as an ongoing challenge. Many in the community did not perceive the various charities and faith-based organizations working maximally with the state and local health departments, local hospital and providers, and they voiced their sense that this represented a lost opportunity. They felt much more could be accomplished if these organizations could work effectively together. The community did, however, proudly point to the fact that many different agencies – with different agendas – work together

to deal with various aspects of social determinants, such as juvenile crime, after-school programs, cultural competency and awareness.

8. Concerns about employment opportunities, particularly for youth, threaten the future vitality of Garden City. There was a worry that the best local talent may leave the area for opportunities elsewhere in the state. The other side of this issue was that many Garden Citians were seeking ways to attract new businesses and training opportunities to their area in an effort to retain their workforce and ensure growth.
9. The availability of culturally competent services was increasing in Garden City. The challenge for many delivering services was to remain flexible enough to accommodate the needs of new immigrants of different cultures while meeting the needs of those already acculturating. Participants frequently said they felt they were aiming at a constantly moving target that challenged where they should invest efforts to meet the needs of recent arrivals. One month, a group of Somalis moved into the area; the next, a new wave of German Mennonites arrived. The dilemma was how to strategically invest resources so the community can meet the needs of these groups over time.
10. **Linguistic services, both in educational environments and throughout the healthcare system, were seen as essential to meeting the needs of minority communities.** The relatively remote location of Garden City fueled the feeling that such training needed to be available to public health and healthcare workers locally. The Hispanic community in particular believed that where someone lives, their age, gender, health insurance status, and primary language were all likely to have a larger contributory effect on health disparities than race alone.
11. The role of faith-based organizations should not be underestimated for the Latino community. Prayer and faith has been reported to be an important value, belief and coping mechanism for many Latinos (Talamantes, Gomez, & Braun, 2000). While on one hand, faith may persuade some that their health condition is not under their own control, reflecting the belief that illness is “God’s will,” it also presents an enormous source of strength and support to Latinos individually and collectively.

“We cannot be one America when a whole segment of our nation has no trust in America.” – President Bill Clinton, May 16, 1997 Apology for the Tuskegee Syphilis Study

“Equal health is out of reach for African Americans in a society that doesn’t value social justice.” –African American Pastor, Wichita, Kansas

KANSAS COMMUNITY PERSPECTIVES – WICHITA

As early as the 1850s, African Americans came to Kansas as both freestaters and former slaves. They were soldiers. They were homesteaders. They were cowboys, driving cattle up the Chisholm Trail. African Americans participated fully in the growth of Kansas and particularly in the 1870s in Wichita’s booming “cowtown.” The African American community in Wichita is a longstanding one, and many families have resided in the city for many generations.

While the African American community has been involved in virtually every aspect of Wichita’s growth, some individuals interviewed for this study had a sense of isolation and, in some cases, a feeling of abandonment by local political and city-based interests.

The historic context of African American influence in Wichita is extremely interesting. Four years after the Supreme Court overturned *Plessy v. Ferguson* and ruled that racially separate schools were not equal, African Americans staged a sit-in at the downtown Wichita Dokum drugstore lunch counter. This protest is described as one of the most effective sit-ins over segregation that occurred across the nation during the summer of 1958. A fascinating history of sit-ins and other racial issues, including profiles of those involved, is the basis of Gretchen Cassel Eick’s book, *Dissent in Wichita* (Eick, 2001).

Throughout the 1950s, African Americans influenced the local community through the establishment of churches, employment in the aircraft industry, and contributions to the growth of other businesses. Like many semi-urban/urban communities, there is a legacy of racially segregated neighborhoods in Wichita. While there is no clear “urban core” *per se*, Wichita’s African American communities tend to be limited to the northeastern area and are less likely to be located in suburban areas around the city. Residential segregation increased during the 1950s

and by 1960, 90 percent of the city's black population lived in seven contiguous census tracts (Eick, 2001).

Health issues that dominate the African American experience include diabetes, hypertension and premature death due to certain cancers. Communities shared their feeling that primary contributors to health disparities include institutionalized and internalized racism, differential access to quality education, and longstanding low standards that have become internalized by the community itself. Communities lean heavily on faith-based organizations and their strong commitment to the total well-being of the individual as they look to the future vitality of their population.

The following list represents core themes and concerns of African American communities in Kansas based on information gathered through focus groups and structured interviews, primarily conducted in Wichita. The list is not presented in rank order.

1. The concept of race is firmly rooted and expressed as political and economic disenfranchisement for the African American community. Consequently, healthcare issues (including access to care, cost of insurance, and availability of culturally competent providers) can be attributed to these predisposing factors, rather than to race itself. **The community repeatedly emphasized their belief that racial health is determined by social and political forces.**
2. Impoverished communities with poor schools, a lack of business opportunities, little local business ownership, and low social capital were considered a disproportionate disadvantage for African Americans.
3. Community members felt they had less chance of achieving good health because they lack role models and positive health messages from a very early age.
4. Modeling change and intervention from a community assets perspective, rather than a deficit model, is considered a critical factor in addressing health disparities at a community level. The Wichita community was embracing this model and moving ahead in critical areas of access to health and healthcare services, such as Project Access.

5. The key to a successful community-based approach to eliminating health disparities rests with leveraging local resources, including African American churches, beauticians, barbers and locally owned businesses. Participants believe using these community-based resources empowers them to institute health improvement and health promotion messages.
6. **Predisposing social factors including education, crime, alcohol and drug use, single family households, teen pregnancy, under-employment and other factors begin the separation of the mainstream population health and health risk of African Americans.** This separation grows to result in the full-fledged health disparities noted at a population level, including early mortality, poor birth outcomes, cardiovascular diseases and diabetes/hypertension. To understand the core issues responsible for health disparities, it was impossible not to talk about incarceration, teen pregnancy, school dropout rates and family structure. These social factors weigh heavily on determining health risks to the African American community. Without a doubt, the Wichita African American community clearly understood the role of social determinants in health.
7. The African American community felt that the issue of health disparities cannot be discussed without discussing both overt and covert racism. Institutionalized racism continues to impact the behavior, policies and financing of health for African Americans.
8. Those delivering healthcare to the African American community interestingly raised their concern that African Americans are largely left out of mainstream clinical trial research. Diseases that affect their populations disproportionately, such as diabetes and renal disease or hypertension, are less likely to be studied using African American patients who might help researchers develop more effective treatment and intervention models relevant to their community. The health services providers felt this left them at a disadvantage, unconvinced of the efficacy of certain treatments.
9. In communities that want to make a difference and address health disparities, locally relevant surveys and data based on their neighborhood, ZIP code or service area were needed. These were rare, and the community was often limited in its ability to collect this information due to costs and limited expertise in how to accomplish such tasks.

10. The health system must respond to minority communities by encouraging community-based clinics, staffed by community members and providers who reflect the community's ethnic and racial composition. Workforce initiatives were considered a key element in improving the health system.
11. Diet, nutrition and exercise were common contributing factors cited in exacerbating health risks among African Americans. **Study participants lamented that few of their neighborhoods have safe sidewalks, street lights or walking trails near enough to be used by those who need them.**
12. In Kansas, African Americans generally live in the most urban, populated areas of the state. Therefore, urban living issues such as lack of public transportation, poor housing standards (i.e., possible exposure to lead paint), and exposure to other environmental hazards contribute to health problems.
13. Particularly for young African American males, a sense of hopelessness and mental health-related conditions destroy the opportunity to live healthy lives. This can be a devastating situation, leading those who need services to cease seeking them. They simply give up. To address this issue, community health leaders argued that the only effective way to reach these individuals was to take health campaigns and health services to the street level. To do so, they stressed that community outreach worker training and pay needed to be addressed.
14. Local health departments currently do not provide effective services to the African American community. Local health departments included in this study acknowledged the lack of cultural competency skills needed to address many minority health issues. Generally, however, those providing public health services tended to think of cultural competence in relation to foreign immigrants and those who do not have English as a first language; **they demonstrated little understanding for the needs of cultural competence in dealing with the African American community.**
15. Finding ways to encourage behavior change at the individual, neighborhood, parish, and/or community level will be the cornerstone to improving African American health. There was a clear sense of self-determination, and a desire for the community to drive the direction and tempo of change concerning key health issues.

16. Health insurance costs and pharmacy costs were shared as key barriers for African Americans. When contrasted against other key financial issues (clothes, food, rent, mortgages, car payments, etc.), individuals may choose to forgo insurance for themselves or their children hoping they will not have a major medical expense. They also short-change drug regimens by using less than the prescribed amount of medication (pill-splitting).
17. **Community leaders have very low expectations that the state of Kansas will tackle the issues of health disparities.** State agencies are seen as bureaucratically ineffective, without leaders who care about local minority health issues. The community believes the dearth of African American politicians at the state level diminishes the chance that minority health will receive much attention. Accordingly, African American Wichitans are focused on improving their neighborhoods and communities themselves, despite the lack of attention or support from others.

“I have to carry two cards just to prove that I’m Indian.” – Native American Community Leader, Kansas City, Kansas

KANSAS COMMUNITY PERSPECTIVES – KANSAS CITY, KANSAS

The American Indian or Native American experience throughout the history of the United States is a difficult one to tell, not only because it was often tragic, but also because the experience was so varied among the many tribes who lived in North America. Many of the original Plains tribes that inhabited Kansas were driven or removed from their land by the western expansion of Europeans. The Kansa (*Konza*), Cheyenne, Arapahoe, Osage, Pawnee, Kiowa, Comanche, and other Plains tribes in the area no longer live in significant numbers in Kansas. Those that remain and those who were resettled here have diverse cultures and histories.

The 1830 Removal Act precipitated a number of actions, including a series of treaties and relocation events for current-day Kansas American Indians. Originally, the Kickapoo lived in Wisconsin and Illinois, the Prairie Band Potawatomi were from the Great Lakes region, the Sac and Fox (*Asakiwaki* (Sauk) and *Meshkwahkihaki* (Mesquakie/Fox) were also from Wisconsin and surrounding areas, and the Iowa were from Missouri. These tribes currently reside on independent reservations; they operate as independent governments and are recognized as sovereign nations. They have their own services including police and fire departments, tribal court, casinos, social services and health clinics.

If a Native American is enrolled in one of more than 550 federally recognized American Indian or Alaska Native tribes, they are eligible for services provided by the Indian Health Service (IHS). The IHS is an agency within the Department of Health and Human Services that provides a comprehensive health service delivery system for approximately 1.6 million of the nation’s estimated 2.6 million American Indians and Alaska Natives. The IHS provides access to healthcare services in more than 45 hospitals and 500 other facilities operated by the IHS, by tribes, by Alaska Native corporations or purchased from private providers. This introduces a unique and complex dimension of health for Native Americans. Their healthcare and health behaviors are characterized by a dynamic network of moving between the IHS, community clinics, federally qualified health centers (FQHC), private providers and charity care organizations. Participants in this study described complex personal health decisions

reflecting where they go for health services. One participant discussed returning to the reservation for IHS services regarding general medical care and for diabetic care including medications; visiting a separate IHS clinic for dental services; using a local provider for mental health services; and attending yet another local clinic for prenatal care, given the distance to the IHS clinic. This complex nexus of services invites poor coordination of care. Because providers do not systematically exchange healthcare information, the individual becomes responsible for telling providers about medications and treatments recommended by other providers.

American Indians and Alaska Natives have long experienced lower health status when compared to other populations of Americans (U.S. Department of Health and Human Services Indian Health Service, 2000). Life expectancy is lower, infant mortality is higher and the rates of death from alcoholism, tuberculosis, diabetes, accidents and suicide are higher than the overall national population rates. Whenever examining conditions that result in death as the measure, it should be recognized that miscoding or missing information on death certificates likely under-enumerate native peoples, so rate calculations are likely modest estimates (Rosenberg et al., 1999).

Environmental issues that most Americans take for granted are lower quality for many American Indians and Alaska Natives. Safe and adequate water supplies and sanitary waste disposal facilities, for example, are lacking in approximately 7.5 percent of American Indian and Alaska Native homes, compared to 1 percent of the homes for the general U.S. population (Environmental Protection Agency).

While the IHS service population is largely rural, many American Indians in Kansas live in an urban setting. Even for those who return to clinics on reservations or who use other IHS service sites, it is estimated that the IHS-appropriated funding provides only 59 percent of the necessary federal funding for healthcare services to American Indians and Alaska Natives using the system, and only 54 percent for those living in the IHS service area of 35 states (U.S. Department of Health and Human Services Indian Health Service, 2000).

This project focused on a culturally diverse group of urban American Indians living in and around the greater Kansas City metropolitan area. Individuals representing the four sovereign Indian nations that have reservations in Kansas (Iowa, Kickapoo, Prairie Band Potawatami, and Sac and Fox) as well as individuals representing at least 10 other (primarily Plains Indian) tribes participated in focus groups or structured interviews. The following lists their central health concerns.

1. Native Americans were granted U.S. citizenship, and with it the right to vote, in 1924 – just 81 years ago. Many in the Indian community feel their concerns are not taken seriously because they have had, and continue to have, little or no political representation or voice in the state.
2. **Virtually all those interviewed expressed concern about mental health issues. Depression, and its relationship to alcohol and drug use, was cited frequently as a central health concern.** Further, Native Americans lament the fact that there are virtually no mental health services in the Kansas City, Kansas, metropolitan area, and very few other providers who understand the key mental health issues for these individuals.
3. Native Americans have the highest rate of diabetes and are more than two-and-one-half times more likely to have been diagnosed than the general population (National Diabetes Information Clearinghouse, 2002). Participants knew from personal experience that many of them go undiagnosed and are at risk for early onset of type 2 diabetes. They shared a generally fatalistic idea that diabetes was inevitable and unavoidable.
4. When the research team shared that mortality rates may be underestimated by as much as 20 percent due to misclassification of race on death certificates (Rosenberg et al., 1999), they were not surprised. As one participant stated, “My sister was born an Indian and died as white” reflecting the fact that her birth certificate information was provided by a family member, but her death certificate was completed by a funeral director. The impact this has on national and state statistics was not lost on study participants.

5. **Unhealthy behaviors, including smoking cigarettes and poor self-perceived mental health are substantially greater among American Indians and Alaska Natives compared to others in the state.** Poor diet, inadequate nutrition, and lack of exercise are known to contribute to the adverse outcomes of diabetes, and these conditions are of concern. Overall, **participants in the study were concerned with what they referred to as patterns of “self-destructive” behaviors, and they stated that these actions had to be understood in the context of the overall sense of helplessness** and inability to display resilience to stress felt by many Native peoples. They feel that their cultures, ways of life and value within society has been so undermined that they retain little hope of being able to maintain healthy cultural identities. “If you felt worthless, were ostracized because of your race, and considered a relic of days gone by, how would you feel?” asked one informant.
6. Native Americans share a concern that several forms of discrimination exist in the delivery of healthcare – by providers, who treat them differently from majority clients, and by a system in which they believe better quality care is a function of one’s ability to pay.
7. Stereotypes of the “stoic” or “unemotional Indian” fundamentally limit the quality of interaction that underpins the delivery of health services. The need for culturally competent workers with an appreciation of the many facets of Indian life that affect health and well-being is substantial.

DATA FINDINGS

The following section provides a summary of health and other characteristics of four primary populations: Asians and Pacific Islanders, Native Americans, African Americans and Hispanics/Latinos. When reading this section of the report, **keep in mind that Kansas data on racial and ethnic minority health status are limited.** Since the number of persons in minority population groups is relatively small in comparison to the total population of the state, rates or differences may be based on a very small number of cases and in some cases, are so small they are not reported. To increase the number of cases in some health or disease categories, rates generally have been calculated using five years of combined data. This allows for reporting a more statistically “stable” number, but it lacks sensitivity to changes that may have occurred within those combined years. This approach is used in many health reports; nonetheless, it is important to qualify the numbers so the reader retains an appropriate context for reviewing these data. State, population density and county level data, when available, supporting each finding can be located in the appropriate topical appendices to this report.

GENERAL MINORITY HEALTH CHARACTERISTICS

Population Characteristics

- Minority racial populations in Kansas represented 3.7 percent of the population in 1900; they now represent 13.9 percent of the population. When *ethnic* minorities were included, the total minority population in 2000 was 16.9 percent of all Kansans.
- The number of minorities doubled from 1980 to 2000 (from 223,637 to 454,421).
- Minority populations grew an estimated 9.1 percent from 2000 to 2003, and the rate was highest in urban areas.
- Kansas is sometimes thought of as a state with many seniors; however, Kansas’ median age of 35.2 years places the state as the 15th youngest among the 50 states. The number and relatively young age of Hispanics/Latinos (median age is 23 years) accounts for this pattern. Kansans who list their race only as “white” had a median age of 36.9 years, which is older than any other group by at least seven years.

Housing Characteristics

- Minority housing units are more likely to be rented than owned.
- High occupancy per room is considered a measure of inadequate or substandard housing conditions; minorities represent 13 percent of occupied housing units but represent 56 percent of units with high occupancy per room.
- Minorities are more likely to report living without kitchen facilities, without complete plumbing facilities, and paying monthly housing costs greater than 30 percent of their household incomes.

Social Determinants

- One in four (24.4 percent) Kansas families with children under age 18 is headed by a single parent.
- Children in single-parent households are five times more likely than children in married-couple families to be living in poverty.
- Single-parent families with children under five years of age are twice as likely to be living in poverty as single-parent families where all children are five years old or older.
- In 2000, there were approximately 21,000 Kansas households that were linguistically isolated (defined as having no one age 14 years or older who can speak only English, or who can speak English “very well”).
- Eighty-six percent of adults age 25 years or older has earned a high school diploma or equivalent.
- In Kansas, 18.5 percent of mothers with live births had less than a high school diploma.

Income and Employment

- Based on 1999 income, 9.9 percent of Kansans live below the poverty level (100 percent of the federal poverty level). Racial and ethnic minorities were two to three times more likely than whites to be living below poverty. Minorities were two to four times more likely to be living in extreme poverty (below 50 percent of poverty) than whites.
- Minorities are more likely to be unemployed than the white population.
- Approximately 10 percent of Kansans were uninsured in 2001.

Disease and Disability

- Selected reportable diseases (chlamydia, gonorrhea, tuberculosis) are higher among minorities (African Americans, and Asians and Pacific Islanders) than they are among whites.
- The incidence rate for HIV is 3.9 per 100,000.

Births

- Teen pregnancy rates have continued to decline from 1996 through 2003. Rates among 10-19 year olds were lowest among whites (27.2 per 1,000) and highest among Hispanics (54.2 per 1,000) and African Americans (51.6 per 1,000).
- Most mothers (64 percent) report their newborn's ancestry as "American." Following American or European, the next most frequent ancestry listed is Mexican. Hispanic ethnicity combines five ancestry codes (Mexican, Puerto Rican, Cuban, Central or South American, and Other & Unknown Spanish). "Mexican" was the largest Hispanic ancestry, comprising 83 percent of all Hispanic births from 1999-2003.
- Low birthweight (infants weighing less than five pounds) characterized 7.1 percent of births in Kansas between 1999 and 2003.
- Infant mortality was 7 deaths per 1,000 live births (1999-2003). All racial and ethnic groups except Asians and Pacific Islanders exceeded the Healthy People 2010 target of 4.5 deaths per 1,000 live births.

Deaths

- The suicide rate for whites was significantly higher than for all other racial and ethnic groups.

Risk Behaviors

- Almost one in four (24 percent) 8th, 10th and 12th graders report having smoked cigarettes in the previous 30 days (1998-2002 data).
- Forty-four percent of 8th, 10th and 12th graders report using alcohol in the past 30 days (1998-2002 data).

- Fourteen percent of 8th, 10th and 12th graders report using marijuana in the past 30 days (1998-2002 data).
- Twelve percent of Kansans report that their health is “fair” or “poor.”
- More than half of all Kansans (57 percent) were overweight or obese (body mass index greater than or equal to 25) (1995-2003 data).
- Only one in five Kansans reported eating the recommended five servings of fruit and vegetables per day for the last month (1995-2002).

CHARACTERISTICS OF KANSAS ASIANS AND PACIFIC ISLANDERS

Kansas Asians and Pacific Islanders have a unique profile of health. They are a very culturally diverse group; in order of their representation in the Kansas population, they include: Vietnamese, Asian Indian, Chinese, Korean, Filipino, Laotian, Japanese and Hmong. The following list identifies key social and health features identified from the data collected for this project.

Population Characteristics

- From 1980 to 2000, Asians and Pacific Islanders experienced the greatest percent increase in population of any racial group, a 219 percent increase mostly occurring in Dense Rural and Urban counties. Fifty-nine percent of this population lives in either Johnson or Sedgwick counties.
- Asians and Pacific Islanders were young. Their median age was 29.1 and 26.7 years, respectively, compared to 35.2 years for the total state population.
- Only 4.3 percent of the population was 65 years and older, compared to 13.3 percent of all Kansans.

Housing

- Nearly one in five (17.8 percent) of Asians and Pacific Islanders occupied housing units that had more than one occupant (compared to 2 percent of whites).
- Asian and Pacific Islander housing was most likely to lack complete kitchen facilities. Just over one percent of their housing units lack kitchens compared to 0.5 percent of the general population.

- Housing units occupied by Asians and Pacific Islanders were the least likely to report being without a vehicle (3.8 percent) compared to the state rate of 5.7 percent.

Social Determinants

- Asians and Pacific Islanders report the lowest level of families headed by a single parent (14.5 percent compared to 24.4 percent for the general population).
- Forty-one percent of Asians and Pacific Islanders reported not being able to speak English “very well” compared to only 2 percent of the white population. Older Asians and Pacific Islanders were most likely to report linguistic isolation.
- About one-fifth of linguistically-isolated Kansas households spoke an Asian or Pacific Islander language. The top eight counties with the largest number of these households were Sedgwick, Johnson, Douglas, Riley, Wyandotte, Finney, Saline and Geary.
- Asians and Pacific Islanders had a lower than average percentage of adults with a high school diploma (75.2 percent), but the highest proportion of adults with a four-year college degree or higher (40.0 percent). In addition, one in five had a graduate or professional degree. These findings refute the “model minority” stereotype of Asians placing enormous social value on education, and points to the likelihood that particular ethnic groups within this population have had different educational experiences.
- Asians and Pacific Islanders had the lowest percent of mothers with less than a high school education (data 1993-2003).
- Juvenile property crime arrest rates for Asians and Pacific Islanders were 802 per 100,000 among 10-17 year olds; this compares to the state rate of 940 per 100,000. Most arrests were for shoplifting, all other theft, burglary and motor vehicle theft. Juvenile violent crime arrest rates were low (72 per 100,000 vs. 120 per 100,000 for the general population).
- Adult property crime arrest rates (2000-2002) were 91 per 100,000 compared to the state rate of 176 per 100,000. Violent crime arrest rates were less than half that of the general population; 26 per 100,000 compared to 56 per 100,000.

Income and Employment

- Per capita income for Asians and Pacific Islanders was the highest among racial and ethnic minorities in Kansas. However, foreign-born Asians and Pacific Islanders were over three times more likely to be living in poverty than their American-born counterparts.
- Asians and Pacific Islanders were the only minority group with adults (age 18-64 years) *more* likely than children to be living in poverty.
- Among all minorities, Asians and Pacific Islanders were least likely to be unemployed. They were most frequently employed in sales and office occupations (27 percent), managerial, professional and related occupations (25 percent), production, transportation, and material moving occupations (20 percent), service occupations (21 percent), and construction, extraction and maintenance occupations (7 percent). Very few of them reported being employed in farming, fishing or forestry occupations.

Disease and Disability

- Asians and Pacific Islanders report the lowest overall disability rate (27.2 compared to 31.0 for the state).
- Asians and Pacific Islanders had the highest reported tuberculosis rate, a rate 25 times higher than that of whites. Most cases were in the state's metropolitan areas, with about one-third of all new cases reported in Sedgwick County.
- There were very few cases of HIV or AIDS in this Kansas population (the AIDS rate is 1.1 per 100,000 for Asians and Pacific Islanders compared to 3.3 per 100,000 for the total population).

Births

- Teen pregnancy was lowest among Asians and Pacific Islanders, and among 15-17 year olds was the lowest of all racial and ethnic groups (see Appendix F-2).
- The Asian and Pacific Islander birth rate was second only to Hispanics (24.8 per 1,000) at 19.1 per 1,000.

- Among mothers choosing an Asian or Pacific Islander ancestry for their newborn’s birth certificate, the most commonly chosen category is Southeast Asian and Pacific Islander which includes Japanese, Hawaiian, Indonesian and Australian ancestries.
- No disparities were identified indicating poor outcomes regarding prenatal care, low birthweight infants or infant mortality.

Deaths

- The age-adjusted death rate from all causes was lowest among Asians and Pacific Islanders. This indicates that these individuals are not dying unexpectedly in their youth. For example, Asians and Pacific Islanders have the lowest age-adjusted death rate and lowest years-of-potential-life-lost (YPLL) rate from coronary heart disease, cancer and diabetes among all racial groups, although it may reflect an underreporting bias.

Risk Behaviors

- Youth reported lower percentages of cigarette use, alcohol use and marijuana use as compared to all other racial and ethnic groups.
- Asians and Pacific Islanders reported the best self-rated health status, with only 6 percent reporting that their health was “fair” or “poor.” They were also least likely to report any activity limitation (4 percent), and reported the lowest levels of overweight or obesity (31 percent vs. 57 percent for the general population).

CHARACTERISTICS OF KANSAS NATIVE AMERICANS

Native American health status is among the worst of any racial or ethnic minority in the United States, but it is often difficult to measure. The data we have in Kansas regarding Native Americans is riddled with gaps, largely because American Indians go unnoticed. In the absence of asking a client or patient to identify their race and ethnicity, many Native Americans are not outwardly recognized as being Native Americans; their populations are so diverse, and the visual stereotype so embedded in misconception, that their race frequently is mistaken for other groups. Even with these limitations, the following lists what we do know from the data regarding the health and social conditions of Native Americans in Kansas.

Population Characteristics

- The Native American population has remained stable at approximately 1 percent of the Kansas population from 1980 to 2000. The 2000 U.S. Census permitted multiple racial category selection, and there was a 13.5 percent increase in the number of Native Americans since 1990. Including the group of census respondents who chose Native American plus another racial category would represent a 115.6 percent increase in the population, an unlikely situation. The most common two or more races combination was that of “White” and “American Indian/Alaska Native.”
- Native Americans were the only minority group to grow at a rate slower than the general population, an increase of only 0.1 percent which is equivalent to an estimated 16 people.
- Only 8 percent of American Indians and Alaska Natives live in counties with tribal reservations (Brown, Doniphan and Jackson).
- The median age of the Native American population is 28.3 years compared to 35.2 years for the general population. The largest number of Native Americans less than 18 years of age lived in Sedgwick, Douglas and Shawnee counties. Combined, these counties had 36 percent of the state’s American Indian and Alaska Native population under age 18.
- Only 5.2 percent (1, 296 individuals) were 65 years and older compared to 13.3 percent of the total population. This could indicate premature death or out-migration.

Housing

- Native Americans had one of the highest percentages of households without telephone service (8.3 percent) compared to the total population (2.8 percent). This has a substantial impact on state and national surveys that are conducted by telephone, leading to under-representation.
- Native American households had the highest proportion of occupied housing units that lacked complete plumbing facilities (0.9 percent compared to 0.4 percent statewide).

Social Determinants

- Thirty percent of American Indian and Alaska Native single-parent families with children under age 18 were living below poverty.

- More than 80 percent of Native Americans complete high school or the equivalent, but less than 15 percent complete a college degree.
- The male high school dropout rate is 42.8 per 100 students compared to 2.3 per 100 students for the total population (2002-2003 reporting year).
- American Indian and Alaska Natives were the least likely group to have passed an advanced science or advanced math class.
- American Indian mothers were 25 percent more likely to have less than a high school education than white mothers.
- Juvenile property crime arrest rates for 10-17 year old American Indians were 431 per 100,000 compared to 940 per 100,000 for the general population. Burglary was the most frequent property crime, followed by motor vehicle theft, shoplifting and all other theft. The arrest rate for violent crime was 73 per 100,000 compared to 120 for the general population. Aggravated battery/aggravated assault was most common.
- The adult arrest rate for property crimes among American Indians was 80 per 100,000 compared to 176 per 100,000 for the general population. The violent crime arrest rate was 64 per 100,000, higher than the total population rate of 56 per 100,000.
- One quarter of American Indian children under age 5 was living below the poverty level in 1999.

Income and Employment

- Unemployment is about twice as likely for American Indian and Alaska Native adults as compared to the general population.

Disease and Disability

- The American Indian and Alaska Native population had the highest overall disability rate in Kansas: 42.6 per 100 non-institutionalized civilians age 5 or older. Native Americans were more than three times more likely to have a physical disability and nearly three times as likely to have a mental or sensory disability as Asians and Pacific Islanders.
- American Indians had the highest percent of their population with a sensory disability. Nearly five percent of civilian, non-institutionalized Native Americans age 5 or older and 20 percent aged 65 and older reported a sensory disability. They also reported the highest

percent of mental disability (7.5 percent). An especially high proportion of American Indian children had a mental disability (8.5 percent of 5- to 15-year-olds). However, among older American Indians, the mental disability rate declined to 10.2 percent and was below that of any other minority group.

- There were very few cases of HIV or AIDS in this Kansas population, but the HIV rate is comparable to the general population (3.0 per 100,000 for Native Americans compared to 3.3 per 100,000).
- Cancer rates were relatively low and likely represented under-reporting by race.

Births

- American Indian teen pregnancy rates were comparable to the state average, and their overall birth rate was the lowest among racial and ethnic minorities in the state (14.3 per 1,000).
- Percent of low birthweight for Native American infants was 6.6, comparable to whites (6.7), but still above the Healthy People 2010 target of 5 percent.

Deaths

- Native Americans (and African Americans) had the highest coronary heart disease age-adjusted death rate (173 per 100,000). Again, with the high likelihood of under-reporting, the actual rate may be even higher. Three in 10 Native American deaths due to coronary heart disease occurred in Shawnee and Sedgwick counties. Fifteen percent occurred in counties with American Indian reservations (Doniphan, Brown and Jackson).
- The American Indian age-adjusted death rate from cancer was 191 per 100,000 which was comparable to the state rate. The cancer rate over time has been erratic, but may have been decreasing over time since 1996; again, under-reporting is suspected. One third of American Indian deaths due to cancer occurred in Sedgwick and Shawnee counties.
- The American Indian age-adjusted death rate for diabetes is 31 per 100,000 which is higher than that for the general population (24 per 100,000), but the rate is based on only 19 deaths (1999-2003 data). This clearly indicates a pervasive condition of under-reporting that belies the actual burden from this disease.

Risk Behaviors

- American Indian and Alaska Native 8th, 10th and 12th grade students reported the highest use of cigarettes (32 percent), alcohol (47 percent, tied with Hispanics) and marijuana (22 percent) compared to all other racial and ethnic groups.
- Cigarette use was highest among American Indians; approximately one in three was a cigarette smoker (1995-2003 data).
- Self-reported “fair” or “poor” health rating was 19 percent, higher than all other groups.

CHARACTERISTICS OF KANSAS AFRICAN AMERICANS

In Kansas, the African American experience has been one of challenges and slow change. Three out of four African Americans live in one of five counties in the state (Wyandotte, Sedgwick, Shawnee, Johnson and Leavenworth), each characterized by relatively high population density and more urban characteristics such as high crime rates and poor housing quality. A national study examining the contributions of major diseases to disparities in mortality identified smoking-related disease among those with low levels of education, and hypertension, HIV, diabetes and trauma among blacks (Wong, Shapiro, Boscardin, & Ettner, 2002). These conditions and others are characteristic of the Kansas African American population:

Population Characteristics

- Until 2000, African Americans were the largest minority group in Kansas; Hispanics now surpass them. In Kansas in 2000, 5.7 percent of the population was African American (compared to 12.3 percent nationwide).
- African Americans had a relatively small increase in population, 3.6 percent, though this still outpaced the growth of the general population (2000-2003).
- Approximately 1 percent of African Americans lived in Frontier or Rural counties.
- Among all persons identifying themselves on the 2000 U.S. Census as African American, one out of 10 reported this race in combination with another racial category.
- More than one in 10 (11 percent) adult African American males between 17 and 64 years of age was in a correctional institution. This increased the African American population

representation in non-urban counties including Butler, Cowley, Ellsworth, Leavenworth, Norton, Pawnee and Reno.

- The African American population was younger than the general population (28.6 years compared to 35.2 years for the total state population).

Housing

- Twice as many African Americans rented their housing units (56.1 percent) as compared to whites (28.0 percent).
- African American households were most likely to have no vehicle (14.7 percent) compared to the general Kansas population (5.7 percent). Most of these households were in either Sedgwick or Wyandotte counties. That equates to nearly 8,000 African American occupied housing units without a vehicle. Wyandotte County had the highest percentage of occupied housing units without a vehicle (11.3 percent), and the number of African Americans climbed to 19 percent without a vehicle in that county.
- Nearly 20,000 African Americans in Kansas lived in housing units with one or more of the following issues: a lack of complete plumbing facilities, a lack of complete kitchen facilities, more than one occupant per room, selected monthly owner costs that exceed 30 percent of the household income, and gross rent greater than 30 percent of household income.

Social Determinants

- There were more households headed by a single parent among African Americans than among any other racial or ethnic group (55.2 percent compared to 24.4 percent statewide). Wyandotte County had the highest proportion of single-parent households, 42.2 percent, and Shawnee ranked second with 31.8 percent.
- Among those 25 years and older, 20 percent did not receive a high school diploma, 32 percent graduated high school, 33 percent attended some college or received an associate degree, 10 percent graduated from college and 5 percent have a graduate or professional degree.
- African American students were more than twice as likely to be suspended as any other racial or ethnic group, and males in general were about three times more likely to be

suspended than female students. African American students had a violent-acts-against-students rate approximately three times higher than the total student population.

- The juvenile property crime arrest rate for African Americans was 1,713 per 100,000 compared to 940 per 100,000 for the total population. The violent crime arrest rate was twice as high as the total population (253 per 100,000 compared to 120 per 100,000).
- The adult property crime arrest rate for African Americans was 541 per 100,000 compared to 176 per 100,000. The violent crime arrest rate was 168 per 100,000 compared to 56 per 100,000 for the total population. It was noted above that 11 percent of adult African American males are incarcerated.

Income and Employment

- Median household income for African Americans was \$28,627 compared to \$40,624 for the state (1999 data).
- Nearly one in four African Americans was living in poverty in 1999, and nearly half of African Americans had incomes below 200 percent of poverty.
- Thirty-eight percent of African American children under the age of 5 were living in poverty compared to 15 percent of same age white children.
- Allen and Crawford counties had the highest percentage of African Americans in poverty (43 percent).
- African Americans with less than a high school education were more than four times as likely to live below 200 percent of poverty than those with a bachelor's degree or higher.
- African Americans are three times more likely to be unemployed than whites (11 percent compared to 3.7 percent).
- African Americans were nearly twice as likely as whites to report being uninsured. They were also three times as likely to report having public insurance coverage (2001 data). South Central Kansas (excluding Sedgwick County) and South West Kansas had the highest proportions of uninsured African Americans.

Disease and Disability

- Nearly 16 percent of civilian, non-institutionalized African Americans reported that they had a condition that made it difficult for them to work at a job or business.

- African Americans reported the highest level of self-care disability, which includes difficulties with bathing, dressing or getting around at home (3.4 percent for age 5 and older and 12.7 percent for aged 65 and older) compared to other racial and ethnic groups. More than one in three adults age 65 and older reported a physical disability, the highest reported level among all racial and ethnic groups.
- The incidence rate of a reportable disease (chlamydia) for African Americans was nearly 10 times higher than that of whites or Asians, and the gonorrhea incidence rate was similar. It has been suggested that these clients seek treatment from public clinics and that these conditions are more often reported than if they were seen in a private doctor's office. All providers are required to report these conditions, but it appears likely that they do not do so consistently, so other factors may affect these disease-specific disparities.
- The incidence rate for HIV for African Americans was six times greater than for whites (15.9 per 100,000 population compared to 2.7 per 100,000 (2000-2002 data)). AIDS was twice as high among African Americans (4.8 per 100,000 population compared to 2.1 per 100,000 among whites).
- African Americans had the highest overall cancer incidence rates. The rate for African American females was slightly less than the rate for white females, but the rate for African American males was 31 percent higher than for white males and nearly twice as high as that for African American females.
- Male African Americans had prostate cancer, lung cancer and colorectal cancer rates nearly 50 percent higher than the same condition in white males.
- African American hospital discharges were higher than for whites and "others" (1995-1999 data).

Births

- The African American teen (ages 10-19) pregnancy rate was 51.6 per 1,000, nearly double the rate for white adolescents (27.2 per 1,000).
- African American infants represented 7 percent of all births, but 13 percent of the state's low birthweight babies and 16 percent of the state's infant mortalities. The low birthweight percentage was 12.5 compared to the state average of 7.1, and six out of 10 of these births occur in either Sedgwick or Wyandotte counties.

- African Americans have a rate of 15 deaths per 1,000 live births, more than twice the rate of infant mortality among whites.

Deaths

- The age-adjusted death rate for all causes was 37 percent higher for African Americans than for whites.
- The coronary heart disease age-adjusted death rate was 173 per 100,000; the state rate was 150 per 100,000. The rate since 1996 appeared to be steadily declining.
- African Americans had the highest cancer age-adjusted death rate (263 per 100,000 compared to 189 per 100,000 for the state).
- The African American age-adjusted death rate from diabetes was three times higher than for whites (61 compared to 23 per 100,000). Seven in 10 of these deaths occur in three counties: Wyandotte, Sedgwick and Shawnee.
- The age-adjusted death rate from unintentional injury was slightly less than that for whites.
- White males were significantly more likely to commit suicide than African American males; however, African American males were 10 times more likely to die from homicide than whites.
- African Americans had the highest years of potential life lost (YPLL) due to all causes before age 75 (10.8 percent of YPLL occur in a population that only represented 5.7 percent of the state). They also had the highest YPLL due to coronary heart disease (751 years of life lost per 100,000), cancer (1,590 years life lost per 100,000) diabetes (310 years life lost per 100,000), and unintentional injury (1,235 years life lost per 100,000) (1999-2003 data).

Risk Behaviors

- African American 8th, 10th and 12th grade students reported the lowest use of cigarettes and alcohol compared to all other racial and ethnic groups. Nineteen percent reported using marijuana in the last 30 days.
- African Americans had the highest levels of overweight and obesity in the state (63 percent), calculating these conditions based on their self-reported height and weight.

- Dental sealants are widely accepted as a measure to prevent tooth decay, yet only 4.8 percent of African American third graders were observed to have them compared to 37.0 percent of whites (Kimminau, Huang, McGlasson, & Kim, 2005).

CHARACTERISTICS OF KANSAS HISPANICS/LATINOS

There are more than 188,000 Hispanics/Latinos in Kansas, and they represent 7 percent of the state population. Since 1990, Hispanics/Latinos have increased 101 percent in numbers, and they live throughout the state. While largely of Mexican ethnicity (78 percent), Hispanics/Latinos come from many cultures and countries. Historically, they often immigrated to Kansas as service industry workers, migrant laborers and to work in the meatpacking industry. They left Kansas to return to their countries of origin, and then returned again. Other Hispanic families can trace three or more generations in Kansas. This diversity presents a constantly changing profile of acculturation – with some residents possessing few language and other skills to adjust to American culture, while others can steer through the complex health system with less difficulty. The following list characterizes the Hispanic/Latino population in Kansas. We report here only the statistics for those listed as Hispanic, even though we know from national studies that Hispanics also are represented in the “some other race” category.

Population Characteristics

- The Hispanic population grew by nearly 125,000 from 1980 to 2000 – a 198 percent increase. The population increased 330 percent in Dense Rural counties, driven by a more than 400 percent increase in Finney (Garden City), Ford (Dodge City) and Seward (Liberal) counties.
- In just three years, between 2000 and 2003, the Hispanic population increased by an estimated 24,000 individuals.
- Hispanics may be persons of any race. When selecting a racial category, most (89 percent) describe themselves as “white” or “some other race.”
- Hispanics have the highest percentage of males compared to females (53.6 percent) in their population.

- One quarter (24.6 percent) of all Hispanics in the 2000 census were under age 18. Their median age was the youngest compared to all other racial groups (23.0 years) and to the state (35.2 years). The most common age for Hispanics was 0 (less than 1 year of age).

Housing

- The average household size was 3.49 people compared to the state average of 2.51 people. The average family size was 3.86 people compared to the state average of 3.07 people.
- Hispanics were likely to live in housing without telephone service (3,962 units).
- Approximately one in five Hispanics occupied housing units that had more than one occupant per room. Nearly 3,000 Hispanic households lived with two or more of the following conditions: without complete kitchen facilities, without complete plumbing facilities, and with housing costs that exceed 30 percent of household income.

Social Determinants

- Nearly two-thirds of linguistically isolated households in Kansas spoke Spanish. Finney (16 percent), Seward (13 percent) and Ford (11 percent) plus Sedgwick, Wyandotte, Johnson and Shawnee counties had the largest percentage of such households. The adult population age 18-64 was most likely to have problems communicating in English.
- Hispanic/Latino educational attainment rates were lowest of all minority groups in Kansas. Only 51.7 percent of Hispanics/Latinos had a high school diploma. Hispanic students had the highest dropout rate (3.8 for males). Only 69.4 percent of male and 75.0 percent of female Hispanics/Latinos who entered high school earned a diploma, compared to 88.2 percent of all Kansans. Less than one in 10 (9.7 percent) earned a four-year college degree.
- Over half of Hispanic mothers with live births (52.7 percent) had less than a high school education compared to 18.1 percent of white mothers. Sixty percent of Hispanic mothers in Frontier counties and 59 percent in Dense Rural counties lacked a high school education.
- The juvenile property crime arrest rate for Hispanics was 1,440 per 100,000 compared to 940 per 100,000 for the total population. Shoplifting and burglary were the most common

crimes. The juvenile violent crime arrest rate was 211 per 100,000 compared to 120 per 100,000 for the total population. Aggravated battery/aggravated assault was the most common crime.

- The adult property crime arrest rate was 296 per 100,000 compared to 176 per 100,000 for the total population. The adult violent crime arrest rate was 103 per 100,000 compared to 56 per 100,000 for the total population.

Income and Employment

- One quarter of Hispanic children were living below poverty (1999 data). Over one half of Hispanics had incomes below 200 percent of poverty, twice that of the white population.
- In 2000, one in four uninsured was Hispanic. Hispanics were twice as likely as whites to have public health insurance coverage (2001 data).

Disease and Disability

- Hispanics/Latinos reported the lowest levels of self-care disability (1.6 percent) and among the highest levels of employment disability (16 percent).
- The HIV infection rate was 6.9 compared to 2.7 for whites; AIDS rate was 1.9 for Hispanics compared to 2.1 for whites. Before 1991, only 3 percent of new AIDS cases were among Hispanics; between 2000 and 2002, Hispanics accounted for 15 percent of new AIDS cases.
- Cancer rates cannot be calculated for Hispanics.
- Hospital discharge data were not available by ethnicity.

Births

- The Hispanic teen (ages 10-19) pregnancy rate was 54.2 per 1,000 compared to 27.2 for whites.
- Nearly three-quarters of the state's Hispanic/Latino births occurred in seven counties: Sedgwick, Wyandotte, Finney, Ford, Seward, Shawnee and Johnson (1999-2003 data).
- The Hispanic birth rate was 24.8 per 1,000 live births compared to 14.5 per 1,000 live births statewide. The Hispanic birth rate was highest for Dense Rural counties (27.9 per 1,000 live births).

- Hispanic mothers most frequently chose “Mexican” ancestry for their newborn’s birth certificate (83 percent of all Hispanic births).
- Hispanic women had the lowest first trimester prenatal care rates at 70.3 percent compared to 86.2 percent for the total population. This pattern has been improving, showing an increase from 64.6 percent in 1996 to 70.3 percent in 2003.
- First trimester care varied by ethnicity. Cubans had a rate of 89 percent, just shy of the Healthy People 2010 goal (90 percent). Mexicans had the lowest rate among Latinos at 69.1 percent. One in 10 Latino births in Kansas were to Mexican mothers.
- Hispanic women were least likely to receive “adequate” or better prenatal care (measured as a function of prenatal care visits and when the care began) with a percentage of 63.7 compared to 80.9 percent for the total population. Only 53.4 percent of Hispanics in Dense Rural counties received “adequate” or better prenatal care.
- Low birthweight infants occurred least frequently to Hispanic/Latino mothers compared to the other racial groups; the rate was 6.0 percent compared to 7.1 percent statewide.

Deaths

- Death rates calculated for Hispanics are likely to underestimate the actual number of deaths because of racial and ethnic misreporting. The age-adjusted all-cause death rate for Hispanics was about two-thirds that of whites.

Risk Behaviors

- Hispanic 8th, 10th and 12th grade students reported the highest level of alcohol use in the past 30 days (47 percent, tied with Native Americans).
- Sixty percent of Hispanics reported that they are overweight or obese, slightly greater than the 57 percent for the state. Thirty-five percent had no personal doctor or healthcare provider compared to 17 percent for the general population.

DISEASE-SPECIFIC HEALTH DISPARITIES

CANCER

Cancer is the second leading cause of death in the United States after heart disease, and cancer causes one in four deaths (Centers for Disease Control and Prevention, 2002). Cancer awareness has grown steadily, and many national organizations have helped identify cancer trends in minority populations. Since 1987, the third week in April has been set aside as National Minority Cancer Awareness Week. At this time, researchers and healthcare professionals across the country educate minority populations about cancer and explore why some ethnic minorities are more likely to develop and die from certain types of cancers. For example, the national incidence rate for cancer is 16 percent higher among African Americans than for whites, and other racial and ethnic groups have high rates that vary by gender and age. African American men have the highest rates of prostate cancer and colorectal cancer as compared to the general population, while lung cancer is high among Native Americans (Kansas Cancer Registry 1996-1999 Kansas Department of Health and Environment).

While white women are most likely to be diagnosed with breast cancer, African American women are more likely to die from the disease (Boyer-Chammard, Taylor, & Anton-Culver, 1999). One hypothesis is that African American women either do not seek screening or do not perform self examinations at the same rate as white women and are therefore diagnosed later in the course of the disease. Another hypothesis is that they may seek screening and complete self exams at the same rate, but are more likely to visit providers who are less qualified to make early-stage diagnoses. In either event, the health, economic and emotional costs of this situation are high.

Once diagnosed, disparities in treatment patterns are evident among racial and ethnic groups. Disparities have been identified in the primary treatment of breast cancer, cervical cancer and prostate cancer (Agency for Healthcare Research and Quality, 2003). In each of these cancers, as well as in colorectal cancer, we know that mortality can be reduced by screening and early intervention, but some minorities may not receive these screenings at an optimal time. For example, Asian women in Kansas are half as likely to receive a Pap smear test for cervical cancer than the general female population (Bureau of Health Promotion Kansas

Department of Health and Environment Behavioral Risk Factor Surveillance System (BRFSS)1995-2002). An interesting exception to this pattern is that African American women appear to have higher screening rates nationally for cervical cancer (84 percent vs. 82 percent among whites), and they have an associated lower incidence of presenting to the medical system with late stage cancer (Agency for Healthcare Research and Quality, 2003, p. 21).

Between 1996 and 1999, there were 50,075 cancers reported to the Kansas Cancer Registry, or about 12,500 per year. The overall age-adjusted incidence was 461 new cases per 100,000 population. African Americans had the highest overall cancer incidence rates, and for all types of cancer combined, males had higher rates than females for all races except Asians and Pacific Islanders.

Male prostate cancer had the highest incidence rate, and the rate for African Americans was nearly 50 percent higher than for white males. Lung cancer was still a common cancer, more common among males where the incidence rate is nearly twice as high as for females. African American males had a lung cancer rate that was substantially higher than for white males (129 compared to 87 per 100,000).

In general order of severity, the four cancer states include “in situ,” local, regional and distant. Generally, treatment and recovery is most likely when the cancer is detected early and is still “in situ” or local, compared to when it has affected distant tissues or organs. Most female breast cancers (56 percent) were diagnosed at the local stage. African American women were more likely than white women to have their breast cancer diagnosed at the regional or distant stage (39 percent compared to 30 percent).

The most common stage for diagnosis of colorectal cancer was regional (43 percent) and the most common for lung cancer was distant (45 percent). No racial disparities regarding stage of diagnosis were identified. Racial disparities were noted in the age-adjusted death rates from cancer. The Kansas African American age-adjusted cancer death rate was 263 per 100,000 population compared to the state rate of 189 per 100,000. This was associated with a higher years

of potential life lost (YPLL) rates due to cancer, where African Americans had the highest YPLL from cancer in the state (1,590 YPLL per 100,000 population).

DIABETES

Type 2 diabetes is on the rise nationally. Part of the reason is linked to the increasing prevalence of overweight and obesity, predisposing conditions for the early onset of diabetes in adults, and the trend is projected to continue. While diabetes is a chronic disease, its onset can be delayed and its severity diminished with appropriate medical and personal behavior intervention. Diabetes has been very well studied in minority populations, particularly among Native Americans as well as among Native Hawaiians and Latinos.

When properly controlled, the negative health effects of diabetes can be delayed or entirely prevented. When uncontrolled, diabetes can cause blindness, renal disease, heart disease and stroke, complications in pregnancy, and lower extremity amputation (Agency for Healthcare Research and Quality, 2003, p. 48). It is estimated that diabetes costs about \$132 million a year, including approximately \$40 million due to lost productivity and premature death (Agency for Healthcare Research and Quality, 2003, p. 51).

Individuals diagnosed with diabetes are most frequently African American, Native American and Hispanic minorities and individuals with lower levels of educational attainment (Agency for Healthcare Research and Quality, 2003). Lower extremity amputation due to peripheral vascular disease caused by diabetes is observed at twice the rate among African Americans compared to whites (7.0 vs. 3.5 per 1,000) (Agency for Healthcare Research and Quality, 2003, p. 55), and for some in the African American community in Kansas, this event is common and not altogether unexpected. **Most of the African American youth interviewed for this study could name at least one relative or neighbor who was blind or who had had a lower extremity amputation caused by diabetes.** The commonness of these outcomes makes it extremely difficult to promote good diabetes management and self-care. When the youth of the community not only accept these outcomes, but feel it is inevitable that they, too, will develop diabetes, it is extremely difficult to promote healthy behaviors aimed at avoiding the disease.

The standard of quality care for diabetes is well-established, and it has a number of key elements that include responsibilities by each member of a care team. The care team should include a combination of primary care, specialty care and the patient. When the care team is working effectively, diabetics can lead productive lives and avoid many of the negative health affects of the condition.

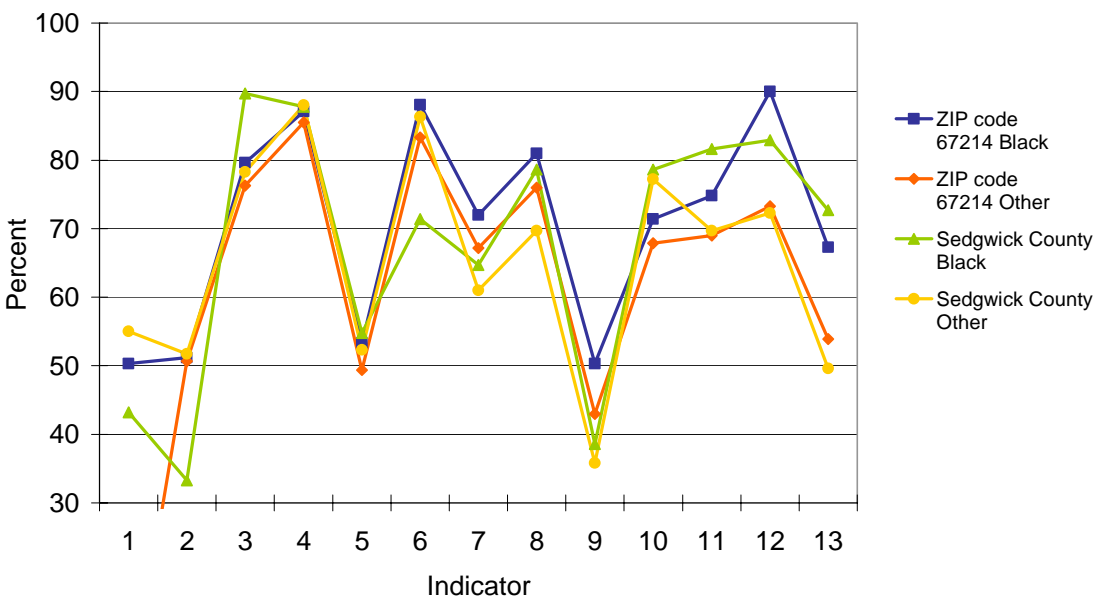
For purposes of measurement, five key process measures are used to assess quality of care. Every diabetic should receive an annual retinal eye exam, annual influenza vaccination, annual HbA1c check (blood chemistry), annual foot exam and biannual lipid profiles. National studies show, however, that only 20 percent of diagnosed diabetics receive these examinations or services (Agency for Healthcare Research and Quality, 2003), and many more miss out on these tests because they have not yet been screened and diagnosed.

Lower-income patients, and African American and Hispanic patients are more likely to be hospitalized for diabetes and its complications than the general population (Agency for Healthcare Research and Quality, 2003). When medical management of diabetes is less than optimal, foot ulcers, infection, and a number of other medical conditions can ensue. The cost of hospitalizations compared to the cost of quality care is not only a financial equation, it also carries a significant quality-of-life dimension.

The Center for Health and Wellness in Wichita has been a partner throughout the Turning Point project. The Center is a community-based clinic founded in 1998 with funds raised exclusively by its Board of Directors and the community. Of the more than 35,000 patients the Center has served, 42 percent are uninsured. Many clients are African American, and diabetes (both diagnosed and undiagnosed) is common. Because of the Center's focus on wellness, screening for hypertension, diabetes and other chronic illnesses that affect the African American community is a priority. Once the condition is identified, the Center's staff and other providers and specialists in the Wichita health system work to bring an individual's diabetes under control through patient education, access to high-quality primary care services and referral to specialists when needed.

In 2002, a diabetes survey was conducted in Sedgwick County that allowed analysis at the county, city and ZIP code level that reflects the area in which the Center for Health and Wellness is located (67214). While we know from national data that African Americans generally have the worst health profiles around key measures of quality of care for diabetes, the study provided an interesting finding. Figure 5 below displays the self-reported results on 12 health status measures including seven directly relevant to diabetic care (indicators 5 through 11).

Figure 5. Diabetes Indicators for ZIP code 67214 and Sedgwick County by Race



Source: Kansas Department of Health and Environment

Note: Indicator 1=Influenza Vaccination, 2=Pneumococcal Vaccination, 3=Counseling about Physical Activity, 4=Cholesterol Testing, 5=Ever Heard of Hemoglobin A1c, 6=Dilated Eye Exams, 7=Provider Foot Exams, 8=Regular Foot Self-Exams, 9=Removing Socks and Shoes Before Seeing the Doctor, 10=Daily Self-Monitoring of Blood Glucose, 11= Examining Home Glucose Record, 12= Frequency of Visits, 13= Appointment Reminders.

On five indicators (HbA1c, dilated eye exam, provider foot exam, regular foot self-exam, removing socks and shoes before seeing the doctor, daily self-monitoring of blood glucose, and examining home glucose records), the data indicate that African Americans in the Center’s ZIP code area equal to or out-perform all other groups. Although the study should be replicated to ensure accuracy, what it does indicate is that there are probable factors that enhance and encourage appropriate care for those with this chronic disease in the community, and at least one

of the factors to be considered responsible for this pattern is the care and education provided at the Center for Health and Wellness.

HIV/AIDS

In the United States alone, almost one million people are infected with human immunodeficiency virus (HIV), and about 25 percent of them do not know that they have the disease (Centers for Disease Control and Prevention, 2001). **While great progress has been made with regard to treatment and prevention, this disease continues to disproportionately affect African Americans, Hispanics and those of low socioeconomic status.** In Kansas, African Americans comprise less than 8 percent of the total population, but they constitute almost 18 percent of the diagnosed acquired immune deficiency syndrome (AIDS) cases in the state (Bureau of Epidemiology and Disease Prevention 2000).

HIV in Kansas is not common. During 2000-2002, there were 318 reported cases. This represents an incidence rate of 3.9 per 100,000, substantially lower than the national rate of 11.8 per 100,000. HIV is more prevalent among males than among females, but for African Americans, there was a higher proportion of HIV cases reported in females than males compared to whites (31 percent female and 69 percent male for African Americans; 15 percent female and 85 percent male for whites). Overall, the incidence rate was six times higher for African Americans and two-and-one-half times higher for Hispanics than for whites.

The median age at diagnosis for HIV was 34 years. Approximately nine out of 10 new cases were to those between the ages of 20 and 49. In 2002, six in 10 new HIV cases occurred in the five largest Kansas counties.

From 2000-2002, there were 234 reported AIDS cases in Kansas. This equaled a rate of 3.3 per 100,000, substantially lower than the national rate of 14.8. Although the majority of reported cases were among whites (66 percent), minorities comprised an increasing proportion of reported new cases. Before 1991, racial minorities accounted for 13 percent of new cases; during 2000-2002, racial minorities accounted for 34 percent of new cases. Hispanics also are increasingly

represented in new AIDS cases. Before 1991, only 3 percent of new AIDS cases were among Hispanics; during 2000-2002, Hispanics accounted for 15 percent of new AIDS cases.

IMMUNIZATIONS

Immunizations are effective in preventing many diseases, particularly diseases that have a devastating effect on children, and they protect everyone in a community. Childhood vaccinations are one of the most successful and cost-effective public health interventions, yet some children go without them and remain exposed to preventable illnesses. **Only 15 states are “universal purchasers” where all children can receive vaccines for free, regardless of their health insurance status. Kansas is not one of the 15 states.** In 1994, the Vaccines for Children (VFC) program was implemented to meet underinsured children’s needs. VFC allows the federal government to purchase vaccine at volume discount and distribute it to states to administer free to children in need. However, underinsured children can only receive free vaccine through the program at FQHCs (Federally Qualified Health Centers) or in rural health centers. The location of the VFC program may still pose a barrier to needy children who live in urban areas or areas that do not have nearby FQHCs.

To be fully immunized, a child needs a series of vaccinations for different diseases, including diphtheria, tetanus, pertussis, measles, mumps, rubella and polio. Nationally, immunization levels are lower among black, Latino and American Indian/Alaska Native children (Centers for Disease Control and Prevention, 2000). Even in states with good overall immunization rates, rates may be lower in larger cities where there are more communities of color (National Conference of State Legislatures, 2000).

Parents may elect not to have their children immunized for medical reasons in all 50 states, for religious reasons in 48 states (including Kansas), and for philosophical reasons in 15 states (including Kansas) (National Vaccine Advisory Committee, 1998). However, children who were exempt were 35 times more likely to contract measles than children who had been vaccinated (Salmon, Haber, & Gangarosa, 1999). Unimmunized children also pose a health risk to others; they have the potential to continue the transmission of the disease to others in the community

who are susceptible, including pregnant women, the elderly and those who are immunocompromised.

Compared to many other states, Kansas ranks poorly on the number of two-year-olds who have received required vaccinations according to *on time* standards. A challenge for our state is that some private providers offer vaccination services while others do not, leaving parents no option but to schedule another visit, generally to their local health department. This fact alone may cause a delay in receiving the appropriate vaccination, as well as creating a time and financial burden on the family in terms of additional time off from work and transportation costs. Administering the VFC program, dealing with private insurance billing, and providing continuity of care for children once they are seen is an administrative burden on even the most efficient local health departments. The infrastructure to deliver vaccinations to children across Kansas is weak. The result? Children eventually get their vaccinations, but often do not receive them on time as is required for high-quality care.

Children are not the only group of Kansans who need immunizations. Statewide, 32 percent of the population over 65 years of age does not receive recommended immunization shots. Racial and ethnic minority seniors are even less likely to have had a flu shot, with 61 percent of African Americans, 54 percent of Asians/Pacific Islanders, 52 percent of Native Americans and 46 percent of Hispanics/Latinos reporting they did not receive flu shots (Bureau of Health Promotion Kansas Department of Health and Environment Behavioral Risk Factor Surveillance System (BRFSS) 1995 1997 1999-2003).

CARDIOVASCULAR DISEASE

Sixty-one million Americans have one or more types of cardiovascular disease, and approximately 950,000 die from it each year (American Heart Association, 2002). Deaths due to cardiovascular disease that occur before the age of 75 are generally considered premature, preventable deaths (American Heart Association, 2002), but we see an increasing number of adults succumbing to these diseases at an early age. While deaths from cardiovascular disease have decreased as a result of reducing the risks associated with smoking and high cholesterol, many more deaths could be prevented. The economic impact alone of heart disease is estimated

to be \$214 billion, including \$115 billion in healthcare expenditures (Agency for Healthcare Research and Quality, 2003).

The leading causes of death in Kansas are related to cardiovascular health. Nationally, cardiovascular disease is the leading cause of death of African American men and women, and four in 10 African American men have cardiovascular disease (American Heart Association, 2002). **Many Kansans are unaware that they have a cardiovascular disease, and they are equally unaware of its life-threatening symptoms. Racial and ethnic minorities are often diagnosed at later stages of the disease process, and may not receive appropriate medical care and follow-up treatment** (American Heart Association, 2002). Nationally, 40 percent of African American women die from cardiovascular diseases and are the highest at-risk demographic group. Twenty-eight percent of African Americans and 22 percent of Native Americans reported being told that they have high blood pressure in Kansas (Bureau of Health Promotion Kansas Department of Health and Environment Behavioral Risk Factor Surveillance System (BRFSS) 1995 1997 1999 2001 2003)

The coronary heart disease age-adjusted death rate in Kansas was 150 per 100,000 population (1999-2003 data). This was lower than the Healthy People 2010 goal of 166 per 100,000. African Americans and Native Americans had the highest coronary heart disease age-adjusted death rate (173 per 100,000), although it is likely that the Native American rate is an underestimate because of poor racial data quality on death certificates. Asians and Pacific Islanders as well as Hispanics had the lowest age-adjusted death rates, but these too may suffer from underreporting bias.

Counties with the highest coronary heart disease age-adjusted death rates included many Frontier and Rural counties (Haskell, 312 per 100,000; Lincoln, 294 per 100,000; Cherokee, 277 per 100,000; Kearny 266 per 100,000; and Morton, 250 per 100,000). Urban Johnson County (along with Gray County) had the lowest age-adjusted death rate at 105 per 100,000.

From 1999 to 2003 there were approximately 82,000 years of potential life lost (YPLL) before age 75 due to coronary heart disease in Kansas. African Americans had the highest YPLL rate (751 per 100,000) compared to the state rate of 648 per 100,000. Counties with the highest

YPLL rates tended to be Frontier and Rural (Woodson, Lincoln, Republic, Cherokee and Greenwood), and counties with the lowest rates tended to be more populated with young Kansans, particularly those that tended to have significant Hispanic populations (Ellis, Riley, Johnson, Finney and Douglas).

MATERNAL AND CHILD HEALTH

The health of mothers and children is critical to the health of the next generation, and we know that prenatal care coupled with appropriate healthcare throughout the first few years of life provides the best chance for a healthy life. There is consistent evidence that events in fetal and infant life can “program” the function of a number of organ systems, and influence adult physical health. For example, illnesses such as coronary heart disease and elevated blood pressure have been directly associated with events in early life (Marmot & Wadsworth, 1997). Infants who are born at term but are small for their gestational age may be at increased risk for adult-onset diabetes, high blood pressure and heart disease several decades later (Hertzman & Keating, 1999).

Disparities in infancy and childhood can increase the likelihood of poor health outcomes later in life. Factors beyond health services influence a child’s chance for future health. Life experiences (sometimes called “pathway effects”) beginning with both health *and* behavioral environments at birth, influence early years and in turn affect school readiness – children who do not have stable, secure and stimulating environments early on are at risk of academic, social and behavioral difficulties in school, of leaving before high school graduation, becoming involved in criminal behavior, becoming pregnant as a teenager, and becoming addicted to tobacco, alcohol and other drugs (Karasek & Theorell, 1990).

The stage is set but not predetermined by prenatal, birth and early childhood conditions. There are many interventions that mitigate pathway effects that impede children’s ability to maximize their health potential. However, all racial and ethnic disparities that impact maternal and child health are particularly crucial if eliminating disparities is a goal. While the magnitude of difference between racial or ethnic groups on various measures may be small, the disadvantage they represent can have a magnifying effect for individuals as they grow and

mature. **Children who start out slightly disadvantaged may be left farther and farther behind their peers over the course of a lifetime.**

Nationwide studies document that black, American Indian and Hawaiian mothers are more likely to have preterm, low birthweight or low Apgar score infants compared to white mothers (Martin et al., 2002). Hispanic mothers are more likely to have preterm infants but less likely to have low birthweight or low Apgar score infants compared to non-Hispanic white mothers (Martin et al., 2002). These patterns are mirrored precisely in Kansas. Many racial and ethnic minorities and less-educated women (regardless of race or ethnicity) are less likely than the general population to receive timely prenatal care, and infants born to African American, Native Hawaiian, Pacific Islander, American Indian and Alaska Native mothers, and to less educated mothers, are more likely to die at birth (Agency for Healthcare Research and Quality, 2003).

In Kansas, maternal and child health indicators demonstrate racial and ethnic disparities. African Americans with dependent children have the highest proportion of single-parent families (55.2 percent) of all racial and ethnic groups in the state. Children in single-parent families are five times more likely than children living in married-couple families to be living in poverty, and the younger the children in the household, the more likely they are to be living in poverty. Unemployment, lack of health insurance coverage, and a relatively high teen pregnancy rate all predict more challenges for children born under these conditions. These conditions may in part be responsible for lower prenatal care rates, more low birthweight infants and higher infant mortality as described in the “Characteristics of Kansas African Americans” section of this report.

Hispanic/Latino mothers do not seek prenatal care services early in their pregnancies. This may be explained in part by their view that such preventive services are unnecessary; they tend to view pregnancy as a natural process and not one of medical infirmity. Even though they do not comply with on-time prenatal care standards, they do not have an unusual number of low birthweight infants (6.0 percent compared to 6.7 percent for whites and 7.1 percent for the general population). The Hispanic/Latino teen (ages 10-19) pregnancy rate is the highest compared to all other groups (54.2 per 1,000 compared to a state rate of 29.3 per 1,000), yet

again, the number of infants born at risk because of low birthweight is not unusually high. While these factors predict poor child outcomes, they do not show a relationship at this point in time. These conditions should be monitored closely over time, particularly because the Latino population is increasing so rapidly in the state.

MENTAL HEALTH

Mental health is an often overlooked dimension of health for all of us. The personal and social costs associated with inadequate care for mental illness is tremendous, and we know that only 25 percent of persons with mental disorders and 40 percent of those with serious mental illness seek help from the healthcare system (Agency for Healthcare Research and Quality, 2003). Further, when patients do interact with the healthcare system, disorders such as depression may go undiagnosed.

The Surgeon General released the *Mental Health: Culture, Race, and Ethnicity* report in 2001, and it documented that racial and ethnic minorities bear a greater burden from unmet mental health needs and thus suffer a greater loss to their overall health and productivity (U.S. Department of Health and Human Services, 2001). The report also stressed that mental health ranks second only to cardiovascular disease in causing disability.

Nationally, most minority groups are less likely than whites to use services, and they receive poorer quality mental healthcare, despite having similar community rates of mental disorders. (U.S. Department of Health and Human Services, 2001). In Kansas, we have a series of measures relevant to mental health. African Americans had a higher proportion of hospital discharges due to mental health disorders than whites. The Turning Point data also pointed to higher rates of disability among racial populations. Four percent of Kansas non-institutionalized civilians age 5 and older reported a mental disability (defined as a condition lasting six months or more that made learning, remembering, or concentrating difficult). This rate is comparable to the national rate of 4.3 percent. American Indians in Kansas had the highest percent of mental disability – 7.5 percent. An even higher proportion of American Indian children had a mental disability – 8.5 percent of 5- to 15-year-olds. This finding corroborates the community's perception that **American Indian youth are suffering from mental illness such as depression. The**

community shared that these children frequently go untreated because of difficulties in accessing care or the total lack of mental health services in their communities.

While these data are indicative of mental health disparities, there are few statewide data sources available to inform this dimension of health. For example, the Department of Social and Rehabilitative Services (SRS) has information on its website concerning mental health services provided to their clients. One project, the Kansas Mental Health Statistics Improvement Project (MHSIP) has produced performance and trend reports for consumers, but does not provide data by race or ethnicity. Other areas of MHSIP are focusing on cultural competence and providing targeted mental health services through special purpose grants to some racial and ethnic populations, such as the Kanza CHMC for American Indians outreach and the COMCARE program in Wichita to provide bilingual and bicultural case management to the Hispanic community. However, there is no single, publicly available document or website to review mental health issues or data for minority Kansans.

“To every complex question there is a simple answer,
and it is always wrong.” – H.L. Mencken

KEY ISSUES OF CAUSALITY

SOCIOECONOMIC FACTORS

There is no standard for how to measure socioeconomic disparities. Researchers use a variety of measures including income, poverty, education, occupation, wealth, and class, although income relative to federal poverty level is most commonly used. However measured, socioeconomic drivers inescapably explain the greatest proportion of the variance in a multivariate model of health disparities. Until socioeconomic factors change, the chance of eliminating disparities is greatly reduced.

Across all countries, poorer generally means less healthy; however, among the 30 wealthiest countries, this relationship is much weaker. One observed pattern is that those with the greatest equity in income distribution are healthier than those with more inequitable distributions (Ross et al., 2000). Many studies document an inverse relationship between socioeconomic status (SES) and mortality (Feldman, Makuc, Kleinman, & Cornoni-Huntley, 1989; Pappa, Queen, Hadden, & Fisher, 1993). What remains unclear is the exact pathway(s) by which SES has an influence on health and why, at critical thresholds, increases in SES have a diminished affect on health (Williams & Collins, 2002).

Even when SES is factored into multivariate models, racial disparities remain (Krieger & Fee, 1994). What this may mean is that other intimately linked factors – factors like racism that remain unmeasured or are unrecognized – are associated with race in ways that influence health.

HEALTH SERVICES

Access to Competent Care

The emergence of “cultural competence” as a body of thought, research and policy in health-related fields represents the intersection of three important trends: 1) the U.S. population is undergoing widespread demographic change fueled by immigration and increases in minority populations; 2) the health status of minorities continues to lag well behind the population as a

whole; and 3) mounting evidence that cultural barriers between healthcare providers and minority recipients make it increasingly difficult for minorities to receive effective and equitable healthcare.

In its simplest and most comprehensive form, cultural competence refers to a professional or service provider's ability to operate effectively and equitably across cultural boundaries. For the purpose of research grants, the U.S. Department of Health and Human Services' (DHHS) Health Research Services Administration (HRSA) defines cultural competence in healthcare as "the level of knowledge-based skills required to provide effective clinical care to patients from a particular ethnic or racial group." Ideally, a culturally competent health provider would be able to provide the same quality of care to members of all racial, ethnic, and cultural groups. Cultural competence is substantively linked to "culturally and linguistically appropriate services" (CLAS), another emerging focus in healthcare delivery settings. A health worker cannot provide culturally and linguistically appropriate services without possessing sufficient cultural competence.

Cultural relativism is defined as the perspective that behaviors should be judged only from the context of the individual's own cultural system. The term refers to the use of your own culture as the starting point to judge other cultures and to the assumption that your culture is superior to other cultures. The goal of cultural competency is to move you beyond your own cultural perspective so you can effectively deal with those raised in a different cultural environment.

Key features of cultural competency include language, bias or stereotyping, and values, beliefs and behaviors. Linguistic limitations present a barrier for effective provider-client relationships. It may prevent minorities from seeking treatment, feeling confidence in their provider, and understanding the provider's messages regarding their health. The consequence of this barrier is that patients may be less likely to follow through with prescribed care, including taking medications as required.

Bias or stereotyping by a provider has been documented to result in less-aggressive treatment (Won, Lapane, Gambassi, Mor, & Lipsitz, 1999), fewer cardiovascular procedures (Ayanian, Udvarhelyi, Gatsonis, Pashos, & Epstein, 1993) and receipt of less prenatal care technology (Brett, Schoendorf, & Kiely, 1994). Cultural competency training attempts to make unconscious biases that influence us in our daily interactions more conscious. Once recognized, they can be addressed and reduced as much as possible. An ancillary aspect of bias is represented by the way we encounter and understand different cultural beliefs that influence health. For example, some minorities may be reluctant to trust the healthcare system due to fear (undocumented persons may be wary that they will be deported if treated in a medical facility), mistrust (African Americans cite the Tuskegee tragedy as an example that earns their mistrust of health providers), and religious beliefs (Muslim women may feel uncomfortable talking about childbirth). Cultural competency's goal is to provide a mental framework for dealing with individuals who do not share our life experiences.

Proponents of cultural competency cite three basic pieces of evidence to support the notion that it is worth the investment of time and money. First, they argue on moral, ethical, and philosophical grounds that the healthcare system is responsible for providing effective, equitable, and affordable healthcare to all people – a common but sometimes controversial assertion. Second, since demographic projections predict an increase in minority populations, the overall health of the nation will be adversely affected by continued disparity in health status. Cultural competence would offer a means of reversing the trend. Finally, proponents argue that cultural competence makes economic sense. Despite the cost of training providers and undertaking other initiatives, cultural competence will result in an improved minority health status and an overall decrease in healthcare costs for the government and the nation as a whole.

Title VI of the Civil Rights Act of 1964 prohibits government disbursement of funds to entities or programs that discriminate based on race, color or national origin. Proponents believe healthcare providers who are not culturally competent are providing a different service to certain minorities, and, since the government is a major purchaser of healthcare and the primary enforcer of civil rights law, it has a significant interest and obligation to ensure culturally competent health services for all Americans.

The second major legal issue related to cultural competence is its potential for limiting liability and malpractice claims against healthcare providers. If healthcare providers cannot or do not properly communicate with patients or perform a culturally competent diagnostic work-up, they leave themselves open to claims of treatment in the absence of informed consent, breach of professional conduct, or even negligence. Proponents of cultural competence cite studies that indicate that thorough, competent diagnostic work-ups and physician-patient communication lessen the risk of malpractice suits.

The third legal issue is cultural competence's relationship to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the DHHS "Privacy Rule" it spawned. The Privacy Rule was designed to protect the confidentiality of individually identifiable health information held by health plans, clearinghouses, and providers who use specific electronic transmissions of personal information. HIPAA is increasingly cited as a reason why providers are uncomfortable in collecting race and ethnicity. To promote cultural competence, data must be gathered about minority health. This requires that the data be kept confidential according to Privacy Rule standards, and, in certain cases, patients must provide consent for the use of personal data that could be used to identify the individual. Minorities who exhibit distrust towards the healthcare system or the government, or who have a limited grasp of the English language, may be reluctant to voluntarily disclose information or sign release forms. Also, once data has been collected or transmitted, it's possible for private entities to misuse health information to "redline" services, deny or drop coverage, or charge higher rates. Knowing, assuming or fearing this, minority groups may be understandably unwilling to select a racial or ethnicity category on patient information forms.

Access to Preventive Health Services

Data document the impact of racial and ethnic minorities' use of urgent or emergency care services, but much less is known about barriers to accessing preventive health services. Critical components to this potential cause of disparities include cultural or ethnic beliefs, culturally and linguistically appropriate service, contextual value of prevention for those targeted, and health system bias.

Some minority cultures do not have a medical model that considers prevention a core element of a healthcare system. These minorities tend to use healthcare services only when they or a family member is sick; they typically don't seek services when they feel well. They may also seek traditional healers before they opt to see Western medical practitioners, or they may seek both simultaneously. In any event, if the avoidance of disease or illness is not a relevant cultural construct, it is very challenging to convince someone that they "need" to be seen by a provider. Even after acculturation, some ethnic minorities may continue to question the value of prevention, particularly if they are young and healthy (i.e., Kansas Latinos and German Mennonites).

If an individual chooses to seek services, these services need to be available in culturally acceptable ways. If people feel they are being looked down on or lectured to, they are not likely to continue seeking services or abiding by the advice given. The Native American community frequently suggested that this is an important barrier in receiving preventive services. They are told not to smoke or drink, to lose weight, and to eat better, but they do not feel that they have the personal control to follow such broad guidance without support. Feeling lectured or – even worse – *blamed* for their poor health only adds to their sense of powerlessness in the face of so many health problems.

Access to Medical Care

Disparities in access to medical care failed to improve from 1997 to 2001, despite a booming economy and increased attention on health disparities (Center for Studying Health System Change). African Americans and Latinos have less access to a regular healthcare provider and are more often publicly insured. Even those with insurance have had to face reductions in benefits and concomitant increases in out-of-pocket expenses. This has been noted as a major factor in delaying dental visits (Kimminau et al., 2005). In addition, once care is sought, minorities may not receive the highest quality treatment available (Randall, 1994).

For racial and ethnic minority populations with limited financial resources, general feelings of hopelessness and powerlessness – coupled with low self-esteem – make it more difficult for them to seek healthcare services. According to the Center for Studying Health System Change,

uninsured whites have greater financial resources, which may explain why they have fewer problems accessing care. **It will be difficult to eliminate disparities in minority healthcare without first eliminating these gaps in minority health insurance.**

QUALITY

One approach to measuring quality of care is to compare whether minority populations receive more or less care than that of the majority population for certain diseases or conditions. This assessment can be distorted in today's healthcare climate, as the majority may be "demanding" health services, resulting in overuse. An additional dimension is to measure equity based on evidence-based standards of care. For example, national data indicate higher use of hospital emergency departments for the treatment of asthma among African Americans than whites. This is considered to reflect poorer preventive and primary care for the disease (Smedley et al., 2002). Hospital discharge data in Kansas may indicate a similar pattern of higher hospital treatment for African Americans (African Americans represent 29.3 percent of all hospital discharges for asthma) (Center for Health and Environmental Statistics Kansas Department of Health and Environment Hospital Discharge Data (1995-1999), 2001). However, this also may be related to the higher prevalence of the disease among African Americans.

The National Quality Forum has suggested a slate of possible health quality-of-care measures for minority care (The National Quality Forum, 2002). The Forum report noted that lack of standardized racial and ethnic categories is a barrier to any manipulation of data to inform health-by-group analysis. They also identified the "small numbers" challenge that creates problems in statistical analysis of quality measures. Nonetheless, the Forum argued for adoption of quality measurement as a key tool in addressing disparities.

The Agency for Healthcare Research and Quality recently released a report titled *Strategies for Improving Minority Healthcare Quality* (Agency for Healthcare Research and Quality, 2004). The study consisted of a meta-analysis of the literature on minority health and quality issues. They reviewed 91 articles that cover two areas: effectiveness of healthcare quality improvement strategies and the effectiveness of cultural competence training. Findings are presented with evidence "grades" that reflect the strength of association and evidence presented in reducing

disparities for racial and ethnic minorities. In the case of effectiveness of healthcare quality improvement strategies, only one area received an “A.” Tracking/reminder systems demonstrated positive outcomes, and there was excellent evidence to support the use of these systems among providers who serve minority patients. A review of the effectiveness of cultural competency training also had one area that received an “A” and that was related to knowledge gained during training for healthcare providers. There was excellent evidence that training increased the knowledge of cultural issues among healthcare providers. Grades of “B” were given to cultural competency programs for affecting providers’ attitudes and for improving their skills in interacting with non-English speakers.

Another aspect of quality is *perceived* quality on the part of the patient. Saha and colleagues (Saha, Komaromy, Koepsell, & Bindman, 2002) explored the degree to which quality was perceived as higher when patient and provider were the same race. While the perception is perhaps not as material as whether the care received actually met best care practices or standards, Saha argues that patients’ perceptions may have a strong influence on whether they continue to seek treatment and care, and that their ongoing behavior towards the provider might yield higher levels of compliance with prescribed care. African American concordance of race between patient and provider had a positive influence on perceived quality, health-seeking behavior and compliance.

GEOGRAPHY

To the extent that the distribution of health resources is nonrandom, geographic location of a racial or ethnic population within the state may be a critical factor in their ability to access and receive services. In a recent study of the dental workforce, KHI identified substantial population density-related patterns among dentists that lead to problems in accessing oral health services, particularly in rural areas of the state (Allison & Bryan, 2005). In at least 10 Kansas counties, there is no dentist in practice, so accessing oral health services requires coordination and transportation. Concomitant oral health status measures provided by another study conducted by the Kansas Department of Health and Environment and KHI identified higher levels of dental decay in rural areas, the same areas challenged by limited dental professional availability (Kimminau et al., 2005).

The Turning Point project reaffirmed the need for state-based, regional and local health data to address disparities. Health and healthcare are local phenomena. Local programs felt that they needed data targeted at regions, primary service areas, and even at the ZIP code level. In some regions of the state, these data are feasible, although currently largely unavailable. Given the number of minority Kansans, county-level data may be adequate to make some inferences regarding minority health. **What communities across the state urged, however, was more comprehensive community-based data that describe their local health disparities.** There is reluctance in accepting state-level data as being directly comparable to their area, and they would always prefer for the data to be collected with large enough samples that their community could be described.

“It is hard to see the future with tears in your eyes.” – Native American speaker at the October 2002 National Turning Point Meeting

POLICY ISSUES FOR KANSAS

A POLICY FRAMEWORK

The central purpose of the Turning Point project was to gather available data that informs the issue of health disparities among ethnic and racial minorities in the state. While there have been concerns and evidence of health disparities among the many agencies, organizations and individuals who serve these populations, the breadth and depth of disparities had not been fully documented and quantified. Furthermore, communities across the state had not been given the opportunity to participate in the discovery process. Communities had not typically been treated as collaborators in the identification of these health issues.

Some of the most effective ways to track health disparities among Kansas’ ethnic and racial minority populations will come not from large expenditures, but rather from sharpening focus on the specific data needs and social issues addressed in this project.

Other initiatives will require collaborative planning, collection and analysis of minority health data indicators. Still others will require strategic investment in information technologies.

Existing public health and healthcare services must be reviewed to determine their current effectiveness in addressing disparities and how (or whether) they can promote community-led change and integration (Public Health Leadership Society Think Tank, 1999). This paradigm shift from academic and provider views to an end-user perspective will drastically change the model in which health is promoted and illness is treated. Our current model of care represents a fundamental frustration shared by many participants throughout this project. **At best, traditional approaches to medicine and to public health do not fully embrace the needs of minorities. At worst, they directly or indirectly continue to reinforce approaches that promote disparities.** Working towards reducing or eliminating disparities will need to take on a holistic approach, with the needs of communities and individuals central to the mission.

Efforts to remediate health disparities must incorporate solutions that address all the determinants of health. While at face value that may appear to be too broad a charge, this report clearly finds that the causes of disparities are fundamentally multifactorial. One policy or one intervention is unlikely to make a substantial difference in the overall picture. Until policymakers accept the multiple dimensions of causality, effecting health improvement will be haphazard, unsystematic and likely only to affect a limited population or group. The concept of a multidimensional approach to disparities is endorsed by various groups (Public Health Leadership Society Think Tank, 1999), and they have coined the resulting structure a “health achieving system.”

The Public Health Leadership Think Tank provided recommendations specific to HRSA’s effort to eliminate health disparities and to institutionalize a “health achieving system.” While these recommendations were intended to be agency-specific, they are worth considering in the broader framework of those in policy-setting positions in the state. The recommendations, modified for a state-level perspective include:

1. **Expand community planning around health disparities** by:
 - a. developing new community health improvement planning initiatives,
 - b. requiring those funded by the state and perhaps those who receive grants from state-based, health-focused philanthropies to invest in local health improvement,
 - c. providing support for community-based health research.
2. **Improve state-level coordination around health disparities** by:
 - a. requiring comparable quality and health status measurements, data or products from state programs (i.e., Healthy Start) and from federal programs administered by the state (i.e., WIC, Medicaid, Medicare),
 - b. creating a new coordinated state investment mechanism in sharing promising or best practices to communities.
3. **Improve collaboration among initiatives focused on health disparities** by:
 - a. coordinating state efforts around disparities (i.e., state office or minority health officer),
 - b. promoting development of an effective system for health status measurement,

- c. facilitating interagency coordination among various bureaus, particularly those that serve the same or comparable populations.

Most recently, an entire issue of the journal *Health Affairs* was dedicated to assessing the progress made regarding health disparities (March/April issue, 2005) since the release of *Unequal Treatment* by the Institute of Medicine. The conclusion from a variety of leading national experts was that despite efforts to reduce health disparities, the impact has been minimal. The main findings from the experts identify that health systems and other social processes continue to sustain the existence of health disparities (a comparable finding was made by this study), and they identified five key issues necessary to move toward eliminating disparities.

1. development and implementation of long-range, coherent, and coordinated strategies
2. collection and reporting of data by race and ethnicity
3. improving healthcare providers' awareness of the problem, strengthening culturally competent healthcare approaches and improving the diversity of the health workforce
4. research into community-based approaches to advance health promotion
5. leadership on the issue from a wide variety of stakeholders, including government, funders, and organizations that represent healthcare constituents

POLICY ACTIONS THAT WOULD BUILD THE STATE'S INFRASTRUCTURE

No single policy action can eliminate health disparities in Kansas, but a multifaceted approach would move the state forward. Each opportunity described in this section is aimed at establishing core capacity and the infrastructure needed to address racial and ethnic disparities.

1. Encourage Better and More Consistent Data

There is no consistent policy regarding the classifications used to collect racial and ethnic information, and the wide variety of data sources exacerbates the challenge. The collection of these data is legal and authorized under Title VI of the Civil Rights Act of 1964 (Perot & Youdelman, 2001), and is essential to eliminating disparities.

Consistency is an absolute requirement of any health dataset. Data dictionaries help define the nature of the data contained in various fields of a dataset, and the rules for their entry. This is critical. It is the only way to track changes that naturally occur over time with regard to the specific field of data being collected. Knowing how to enter surnames, for example, impacts many Latinos because members of the same family may not share the same surname, or there may be two surnames, and the person doing the data entry may not always put them in the correct order. This may seem a small and easily resolved issue, but it presents itself all too frequently. For example, at a recent Kansas Medical Assistance Program Combined Physician and Hospital Task Force meeting (July 2004), the minutes reflect a discussion of this very point. The issue for this group was that the lack of consistency in how surnames are entered, and differences in standards between programs – for example between Medicare and Medicaid – make it hard to identify a specific beneficiary. If this presents practical challenges for these programs and the delivery of services, imagine the impact on entire datasets if names are inconsistently entered. Tracking a minority population’s health services utilization, for example, may default to assuming there are more recipients than there really are in the program. Naming convention and data entry variability may allow one individual to be counted more than once, resulting in inaccurate reporting.

Different standards for data collection wreak havoc on comparing health statistics from different sources. For example, without state or federal mandates, hospitals, individual providers and state-run programs such as Medicaid or HealthWave may each choose different ways to categorize race and ethnicity. The available data from the Kansas Hospital Discharge dataset only permits analysis among “white,” “black” and “other” racial categories and does not include a field for ethnicity. By contrast, birth certificate vital records collect data in a field designated as “ancestry” in the form of an open-ended question that allows for the inclusion of a vast array of ethnic, religious, geographic and other descriptors. This discordance prevents researchers from assessing the same population throughout the life course and diminishes the value of having spent the time collecting the data in the first place.

It should be clear from this discussion that much of the data presented in the appendices of the *Data and Chartbook* likely suffer from many flaws. The source data were examined and

included because they *at least* collected data at the level of race and/or ethnicity. This does not mean that the quality or value of the data is very high. Problems include different standards of data collection, attention to required reporting formats or specifications, lack of verification of accuracy (i.e., self-identification vs. classification by another person) and a general apathy or lack of attention to the importance of accurate racial and ethnic designation. A cardinal rule in the field of informatics is that data only improves or maintains its value if it is important to those collecting it and/or it is actively used for quality improvement, monitoring or other critical aspects that influence the operation of the collecting organizations. If these conditions do not exist, there is no reason to believe that data will be valuable or accurate.

Among many other reasons to collect and analyze data, minority health monitoring cannot be achieved without it. If the state wants to improve the quality of healthcare for Kansans by informed consumer choice regarding the performance of health plans, hospitals and providers, the same data are necessary. An eye to minority health not only does not detract from this complimentary goal, but it adds depth and value to the analysis from a population-wide perspective.

The Healthcare Data Governing Board is a legislatively mandated group charged broadly with ensuring that the state collects, analyzes and uses healthcare data effectively. Composed of members representing various health and business interests, the Board has yet to provide a strategic plan for public health or healthcare informatics for the state. It has not produced a single, unique data report on the health of Kansans. Recently the Board endorsed the use of the federal OMB 15 racial and ethnic categories. However, without enforcement powers or authority, it can only recommend compliance with this most basic level of data collection. Along with race and ethnicity information, data collection on primary languages should be encouraged or required of all Kansas healthcare providers. The opportunity to leverage the Governing Board's mandate to address the extensive healthcare data needs for the state exists, and this group is poised for leadership on the topic of health disparities.

2. Monitor Health Conditions

Development of incidence and prevalence data by race and ethnicity would substantially improve the ability to monitor changes, both positive and negative, with respect to disparities. The state does not have adequate data about the burden of disease, illness and injury relevant to minority health. The limited number of disease registries limits the ability to do small area analysis or to target studies on relatively small populations such as Asians and Pacific Islanders, or particular ethnic Latino populations in Kansas. No registries exist for asthma, disabilities, or birth defects, and the immunization registry implementation has lagged for years.

Small population numbers make identifying disparities a challenge. Because certain populations are small in number and their geographic distribution is widespread, specific types of sampling must be applied to generate reliable estimates of health indicators. Unstable estimates caused by small sample size create less confidence in the reliability of patterns observed. The state could make such sampling correction a key element of doing surveillance and monitoring of disease. This is important: Quality research techniques that yield robust results are essential for building sound policy.

3. Develop Minority-targeted Health Programs

Communities struggle to identify programs, interventions and processes that lead to effective health change and health improvement. Many programs are home-grown, and the staff implementing such programs frequently lament that they are unaware of the successes and failures of similar programs attempted in Kansas or nationally. They are committed to encouraging change through health promotion and obviously do not want to attempt an intervention already proved to be unsuccessful. During the Turning Point community data training activity, participants were unprepared to access available information on the web. Such information could help inform the development of logic models or it could aid in making intervention modifications to ensure the success of their programs. Further, they lacked the ability to measure a program's effectiveness in addressing the health disparity or health issue of interest.

Programs designed for the general population may not be effective if they are not specifically targeted at the needs of minority populations. Any number of barriers or issues might intercede and prevent the same outcomes as were achieved when the program was completed on a non-minority population. This issue is further complicated by the fact that successful interventions are sometimes not publicized or published. There may also be a lack of willingness to accept programs developed outside the local area. State-based programs, supported by various federal agencies, may be commissioned to reach the general public health population and may fail to address the needs of minority populations. Funders may limit the ability of states to offer programs that are responsive to various constituent groups. Under-funding is endemic at the level of state health agencies; delivering a health promotion or disease prevention program that responds to the needs of minorities may simply cost too much.

Minority-targeted programs need to be rigorously evaluated to establish whether they yield positive results. Equally important is the need to identify interventions that do *not* work to reduce disparities. Evaluation generally is an afterthought to executing an intervention program; however, many funders currently require grantees to establish a logic model and an evaluation plan as a condition of funding. These requirements improve the chances that interventions and programs aimed at particular health issues or social determinants will result in objective measures of success.

Communities consulted during the project are anxious to have accurate and reliable data that can be used to address health disparities. They clearly want to use information strategically, and are unanimous about not wanting to replicate an unsuccessful program. Barriers they face include limited knowledge of where data and program evaluation information exist, how to interpret data, and how to measure the impact of programs designed to reduce disparities and improve health. These deficiencies can be mitigated by regional support and training offered through local health departments, local hospitals and other health delivery systems.

State health departments and offices could serve as a catalyst for “promising practices” dissemination of interventions targeted to minority communities. In collaboration with other partners, various bureaus within the Kansas Department of Health and Environment, the

Healthcare Data Governing Board, health professional organizations (i.e., Kansas Medical Society, Kansas Hospital Association, Kansas Nursing Association, etc.) and at least four state-based, health-oriented philanthropies could work collaboratively to spread, through a variety of mechanisms, initiatives and interventions relevant to reducing racial and ethnic minority disparities. While many of these organizations feel they are doing what they can, there is no commission, no office within state government, no public-private partnership venture – no real attention to the breadth of the issue – that serves as a catalyst or clearinghouse to move the state forward. **Until there is a clear, collaborative and definitive will to organize around the issues that cause health disparities, these strategic partners are less likely to improve the situation as much as they would like.**

4. Improve the Workforce

Compassionate providers who display tolerance and understanding for cultural differences and sensitivity to minority populations are essential to an effective health system. Curriculum to train health providers in cross-cultural skills, cultural competency, cultural brokering, linguistic skills and interpreting services are essential to meet the needs of a diverse service population. One dilemma is that medical, dental and allied health professional curricula are already so intensive in clinical and delivery services that there is precious little time to include separate courses on these topics. While alternative approaches must be sought, integrating racial and ethnic health concerns *throughout* current curricula would likely be more effective than delivering stand-alone training for these individuals.

We know from many studies that patients prefer to be seen by providers who are most like them – preferences for same race, ethnicity, and gender have all been documented. To assess the ability for the medical system to meet this need, data from the American Medical Association for the state is presented in Table 3. These data demonstrate that very few practicing physicians are non-white. In addition, the table includes the number of newly trained physicians in Kansas during the same time period. While not all these doctors will end up practicing in the state, many will, and they mirror the diversity present in the state with two exceptions. First, racial minority graduates, particularly Asians and Pacific Islanders, are over-represented in the graduating classes, while ethnic minority graduates are slightly under-represented. This overall pattern is

doubtless a response to active recruiting and retention efforts for qualified minority students. Over time, this will have a positive effect on diversity, and it represents a commitment to better match the workforce with the needs of the population it serves.

Table 3. Number and Percent of Nonfederal Physicians by Race for Kansas and the U.S.

| | KS # | KS % | U.S. % | KS Graduating # | KS Graduating % | KS Population representation % |
|--------------------------------|-------|-------|--------|-----------------|-----------------|--------------------------------|
| White | 3,527 | 56.3 | 49.4 | 117 | 76.5 | 86.1 |
| Black | 100 | 1.6 | 2.6 | 9 | 5.9 | 5.7 |
| Hispanic | 122 | 1.9 | 2.8 | 9 | 5.9 | 7.0 |
| Asian/Pacific Islander | 445 | 7.1 | 9.3 | 16 | 10.5 | 1.8 |
| American Indian/Alaskan Native | 5 | 0.1 | 0.1 | 2 | 1.3 | .09 |
| Other | 158 | 2.5 | 2.5 | NR | | |
| Unknown | 1,913 | 30.5 | 33.4 | 0 | | |
| Total | 6,270 | 100.0 | 100.0 | 153 | 100.1 | |

Source: <http://www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi?action=compare&category=Minority+Health&subcategory=Minority+Nonfederal+Physicians&topic=Distribution+by+Race%2fEthnicity>
Number of graduates 2002-2003

All licensed providers of health services require appropriate training to meet the needs of an increasingly diverse Kansas. Many professions specifically require continuing education. If professional associations would endorse the need for cultural competency, diversity or linguistic sensitivity training, the awareness levels among those currently delivering care would skyrocket. While recruiting and retaining a diverse workforce is the most positive outcome, training current providers of public health and healthcare services about the needs of racial and ethnic minority populations in Kansas would seed a shift in perspectives – followed by the potential shift in availability and quality of care received by these populations.

In addition to continuing education credits, there is a clear and ever-present need across the state for technical assistance in matters related to minority health disparities. With cuts in state

and sometimes local program budgets, materials in different languages are not always available, and professionals trained in critical areas are not always available to those who need their services or guidance. In the absence of a central technical assistance center such as an Office of Minority Health, local public health and health providers, along with many social service agencies, are left without support. This is seen as a huge disadvantage by participants in this study, as it leaves them to “reinvent the wheel” all too frequently. They sincerely do *not* want to waste resources or their staff and their clients’ time; for example, they do not want to end up with useless data collected from a poorly designed survey. They face incredible challenges in attempting to find free or low-cost assistance in meeting their needs for effective intervention and program development, evaluation and monitoring. Here again, it can be argued that a coordinated, multi-sector, public and private partnership initiative could bring to bear the resources needed to fill this gap.

The state Department of Health through the Office of Local and Rural Health has funded and provided medical interpreter training across the state for the past few years. These trainings are very well received, and more than 450 medical interpreters have attended. Ensuring a linguistically competent workforce and availability of interpreter services is a cornerstone to meeting the needs of many racial and ethnic minority Kansans. The commitment to provide regional trainings across the state already has made a huge difference to the quality of interactions and has boosted feelings of respect and deserved attention for many Kansans who either do not speak English well enough to communicate with a provider or do not speak English at all. These programs need to be funded and continued, constantly re-evaluated for efficacy, and maintained as Kansas continues to diversify.

5. Establish an Office of Minority Health

Forty-five states plus the District of Columbia have a designated governmental authority charged with addressing minority health. **Kansas is one of only five states in the nation without an office of minority health or a comparable official organization.**

States with minority health offices use them for many purposes. Some offices launch disparities awareness campaigns, provide cultural competency training, translate health

promotion materials into various languages, rally financial and other support for initiatives or serve as a hub for grants and scholarships. Nebraska's office handles advocacy and awareness; cultural competency; policy development; resource identification of grants for community needs; technical assistance and training to agencies and communities in grant applications and planning efforts; and promotes collaboration within the health system of state and local departments, community-based agencies and existing programs. In Oklahoma, where the number of Native Americans is quite high, the Office of Minority Health works with local and national minority healthcare initiatives through collaboration with local community organizations and with the federal government (Region VI of the U.S. Public Health Services (Kansas also belongs to this Region)) on a variety of services including the organization of taskforces, the provision of technical support to communities, cultural competency and diversity training, and violence prevention. Interestingly, Colorado also was a Robert Wood Johnson Foundation Turning Point recipient, and they used their grant to establish an Office of Minority Health.

Although the current Secretary of Health and Environment has a staff member designated Minority Liaison, the lack of an office of minority health in Kansas testifies to the absence of a statewide action agenda that would focus attention in this area.

6. Build Accountability

Weaving a minority health focus into the fabric of public health delivery and the purchase and delivery of healthcare services by the state – particularly for medical and social services covered by Medicaid – would ensure attention is given to health disparities.

The way to address many issues that impact the health and well-being of minority communities is by changing the environment and current culture in which healthcare is delivered. In the context of public health, many local health departments are acutely aware of their limitations in delivering interpreter services, cultural competency and diversity training for their workforce; in collecting relevant data; and in monitoring minority health issues in their communities. There is an opportunity to use the relatively recently formed local health department regions as units to receive funding, support and training on issues relevant to the minority populations they serve. Sharing resources (for example, pooled medical interpreter

services, shared minority client surveys, translated health promotion materials) is both cost-effective and likely to improve the consistency of care delivered by these providers.

The Center for Medicare and Medicaid Services (CMS) requires that Medicaid and Medicare clients receive culturally and linguistically appropriate services (CLAS), and CMS provides guidance for CLAS assurance. For example, state contracting and contract renewals with health plans is supposed to be contingent upon successful achievement of performance targets. These targets have been in place since 1998 and include demonstrating effective service, equitable access and comparability of benefits for various racial and ethnic groups. Racial and ethnic consumer awareness of, and participation in, health plan benefits, appeals procedures, and ombudspersons is compared to the rate of grievances and complaints among population groups. All these measures are designed to ensure health plan accountability in addressing minority health, but the federal Office of Minority Health encourages providers to familiarize themselves with the standards, review the surveys and incorporate them into their practices.

The extent to which CLAS has promoted culturally and linguistically appropriate service delivery is not available in the form of a report to the public. While the state's Quality Improvement Organization, currently the Kansas Foundation for Medical Care, reviews and reports complaints about the quality of care Medicare patients receive, public reporting does not include cases by race and/or ethnicity of the patients.

Beyond requirements by the federal government, the healthcare delivery system has a responsibility to ensure equity in care. Provider surveys that encourage self-assessment of cultural competence are available, and include questions on the use of culture-specific assessment and treatment approaches, providing clients with materials translated into languages that reflect the linguistic diversity of their service area, and many other social and behavioral dimensions of healthcare (Mason, 1995; Weiss, 1994). Social and behavioral sciences teach us that until an individual personally recognizes an issue or attitude, it is unlikely that it will change. **Awareness campaigns, self-administered assessments and other approaches that lead to greater acknowledgement of bias, disparities and overall health conditions of minority patients are critical to encouraging positive change.**

Accountability also has a financial dimension. Health systems may find that developing and implementing culturally competent systems of care are consistent with the “business case” of increasing market share among racial and ethnic minority populations. **Purchasers of healthcare are increasingly likely to be from a minority population, and becoming responsive to their needs makes good business sense.** For example, the 2004-2005 legislative session is considering an expansion of the State Children’s Health Insurance Program (SCHIP), and at least part of the consideration for this reform is to address meeting the healthcare service needs of many uninsured Kansas children in a cost-effective manner. Without insurance, these children may go without preventive or routine care, and when they do become ill, they may require more expensive services than would have been associated with prevention. Recognizing the fact that many of these children are not only poor but also likely to be members of racial and ethnic minority populations across the state would add another dimension to the policy debate. For instance, knowing these children live in their political districts might encourage some policymakers to adopt a supportive position on a health policy issue. When they realize their communities are touched socially and financially, they have a practical reason to act. State legislative activity is rarely cast in the light of its impact on ethnic and racial minorities, yet in virtually every case of health reform or health initiative, the impact on these populations is inevitable. Without attention to the specific impact these policies would have on minorities, unintended consequences or purposeful ones might not be detected.

7. Support Communities

Above all, communities across the state want to control their destiny, and to do so effectively, they know that they must learn ways to eliminate disparities. The project participants are intensely proud of the steps they and their communities have taken to tackle the social determinants of health for minorities. As well, they are doing the best they can at meeting the actual health services needs of these populations. They want state and federal agencies to support a model of what one participant called “community-determined solutions to community-defined health issues.” They want funders (generally state or federal agencies, but philanthropies, too) to think more from a grassroots level up, rather than from the agency’s point of view down to them. Their argument is that categorical or “silo” funding limits every community’s ability to respond to local issues and concerns. When they do not feel like partners in the discovery process of

defining their own community's needs, they most resent the intrusion of state or federal guidance.

Synergy could be created by tapping the collective abilities and talents of federal and state agency staffs who could help bring communities interventions, processes and tools to address a broad array of social determinants. These and other partners could provide guidance on, and local tailoring of, population-specific or disease-specific interventions that work. **A coherent and coordinated system that fully engages all participants is most likely to gain the respect and support of the communities who, in the end, will be the driving force in promoting an equitable and positive health environment for all their citizens.**

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