Diabetes Health Disparities in Rural Kentucky

Kentucky Public Health Leadership Institute Scholars:

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EXECUTIVE SUMMARY:

The Equalizers are two nurses working with patients in different settings in separate parts of the state: one working in the community outreach department of a small medical center in Eastern Kentucky and the other in a school setting, with some volunteer time in a free medical clinic in Central Kentucky. While one nurse is working hard to provide health screenings and preventive services, the other one is seeing how diabetes impacts those in an indigent setting where many of the patients served have less than a high school education. She sees a barrier created by this limited education that can only be overcome by facilitating the successful navigation of children through school. Both are seeing the impact of diabetes on our communities, our health care resources, and the ever increasing epidemic that shows no signs of declining.

It has been noted that this millennium generation may be the first to suffer a shorter life span than their parents, and certainly diabetes is a major contributing factor. This project hopes to identify specific gaps in care and services—particularly for patients with diabetes who live in rural areas—and use that information to develop effective strategies for improving disease control and preventing the development of diabetes in patients with multiple risk factors.

In order to identify these gaps, we "took it to the streets" (and the mountains and the hollers) in an effort to obtain accurate information from the target population. We developed a survey of 24 questions designed to obtain information on educational level, income, age, gender, A1C level, diabetes self-care, and opportunities for diabetes education. Our survey was designed and administered using Survey Monkey, one of the world's leading providers of web-based surveys. Participants also had the option of using a "hard copy" survey if they preferred as Survey Monkey allowed us to enter the surveys manually as we received them. Diabetes educators, diabetes support groups, diabetes coalitions, churches, local health departments and our present and past KPHLI co-horts helped us distribute our surveys and we had a total of 279 participants.

We also used Survey Monkey to analyze our data. The program gave us a composite of the responses to each question and also the capacity to cross-tabulate responses. For example, using educational level as a control question or independent variable, we could cross-reference that with A1C levels or whether or not a participant had health insurance to determine the impact of educational level on that specific dependent variable. For our project, we were particularly interested in income and educational level as our independent variable or control questions, and the relationship these variables have on A1C level, perception of how well patients are controlling their disease, who their providers are, and what are the most challenging aspects of their diabetes care.

We now have some very rich data that can be shared throughout the state. The capacity for cross-tabulating this data is overwhelming and we are still in the process of exploring some of these relationships. But, we have succeeded in identifying some very specific gaps and can now focus on developing some effective strategies to bridge these gaps.

INTRODUCTION/BACKGROUND:

Kentucky leads the nation in many high risk indicators. Based on data from the Kentucky Cabinet for Health and Family Services (2009) our rate for diagnosed diabetes is 9th highest in the nation with an estimated 324,000 adults having the disease. Many factors contribute to the

prevalence of diabetes. High obesity rates (30% of adults in Kentucky) and sedentary lifestyles (30% of adults reporting low rates of physical activity) increase risks for development of this chronic condition. High blood pressure and high cholesterol increase disease likelihood and nearly 40% of adults in Kentucky have hypertension and 30% report elevated cholesterol levels. Historically the incidence of diabetes has increased steadily over the years. Many factors contribute to that shift. Significant time and resources are dedicated to obesity prevention and reduction efforts. One should question however, if all these efforts are channeled in the right direction? An article by Freudenberg and Ruglis (2007) discusses the link between health and educational achievement and how public health professionals rarely make reducing the number of students who drop out of high school a public health priority. In the United States nearly one-third of all students and half of black, Latino, and American Indian students do not graduate from high school on time. In Kentucky, African American and Hispanic dropout rates are greater than that of white students. The white dropout rate slightly decreased from 2.94 in 2007 to 2.88 in 2008. For African American students that rate was 6.14 in 2008 and 6.10 for Hispanics -over twice the rate for whites. (Kentucky Department of Education, 2009). In general, African Americans in the state have a higher prevalence of diabetes than whites with 17.4% of the adult African American population having diabetes which is about two times higher than for White Kentuckians (Cabinet for Health and Family Services, 2007). Data from the Centers for Disease Control and Prevention reports that diabetes disproportionately affects Hispanics in the United States and rates increase with obesity but the rates decreased with higher education levels. Among Hispanics with less than a high school education, 11.8 percent had diabetes compared to 7.0 percent of college graduates. The cost of diabetes for Kentucky in 2002 was $2.9 billion dollars.

Kentucky has "topped" the poor health list for a number of years. Diabetes, cancer, obesity and sedentary lifestyles have been problems focused on by health care providers, the public health workforce, hospitals and advocate groups, and although successes can be measured efforts are not stemming the tide of unhealthy lifestyles and the associated burden to already taxed resources.

This project is the result of two nurses concerned about outcomes for those with diabetes in Kentucky who have questions regarding the kinds of gaps that exist in rural areas.

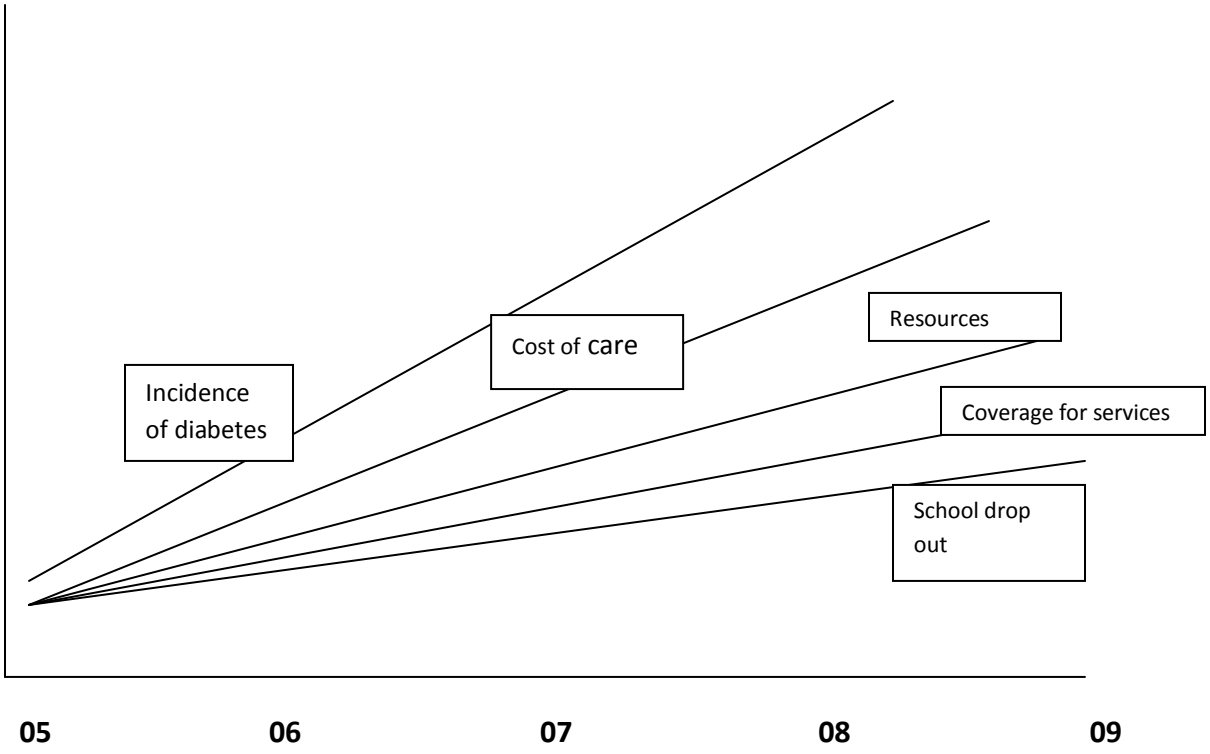
Problem Statement:

Is there is a gap in ***prevention and treatment*** of diabetes in Kentucky between low income and other populations in Kentucky?

Although both group members had an interest in gaps in health care for those with diabetes, there were differing perspectives from which those concerns were viewed: one working in the community services department of a medical center and the other in a school setting, with some volunteer time in a free medical clinic. After much discussion group members concluded that both had the final goal of empowering patients to improve control of their health. Although both feel there are gaps in care for patients with diabetes, little data is available regarding the root cause of these gaps. Is it lack of access or lack of literacy? Does high school graduation translate to an improved A1C as a measure of diabetes care? Does the diploma lead to improved financial resources? With these questions in mind we set out to gather information from rural areas in

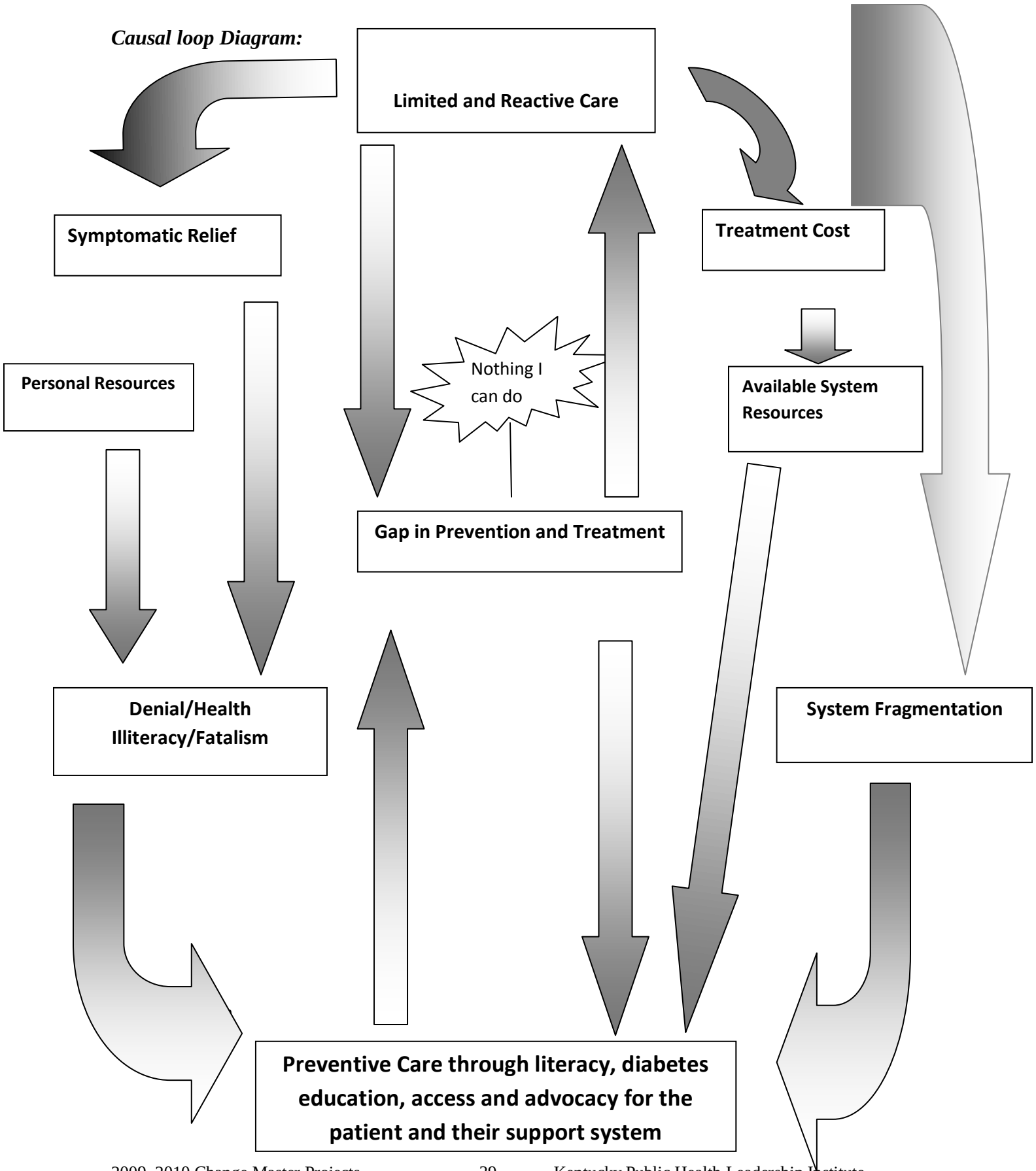
Kentucky to see what barriers persons with diabetes who live in rural areas are facing and see if these barriers seem to have anything to do with education level and socioeconomic status.

Behavior over time graph:



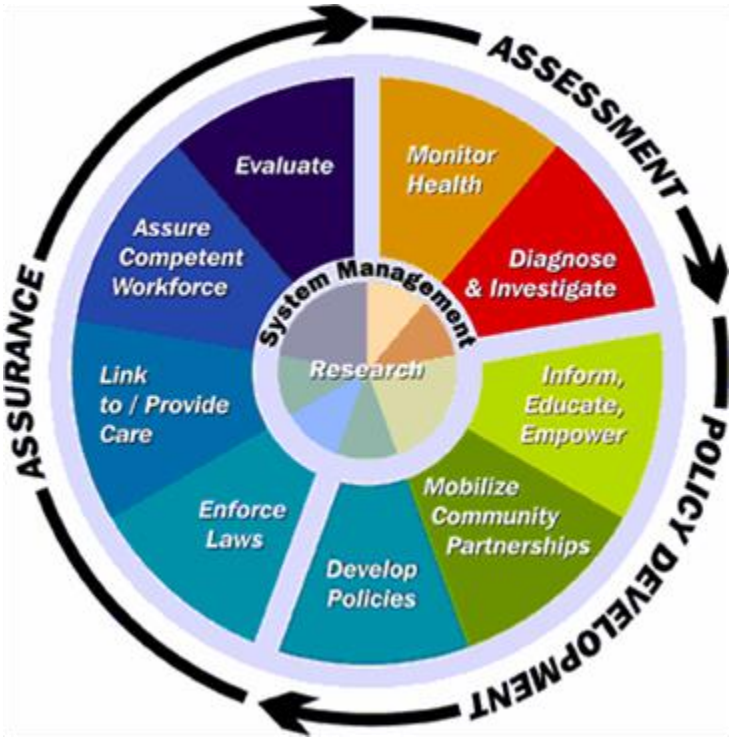
The Behavior-Over-Time graph is a schematic depicting variables which have changed over time and the group perception as to how those have changes. The incidence of diabetes has been increasing over the years as has the cost of health care. Resources seem to have increased somewhat but not at the same rate of incidence and cost. Coverage for services certainly has not seen congruent increases and school dropout also seems to be a variable that has not increased dramatically but has neither seen much decrease.

Causal loop Diagram:



The causal loop diagram shows that much care for diabetes is limited and reactive. A great deal of time and effort is spent in provision of care as opposed to prevention, and there are gaps in prevention and treatment. The left side of the diagram focuses more on preventive efforts--factors that can be impacted by variables such as high school completion or college education. Personal resources are expanded with increased opportunities available through education. Health literacy can be affected by improved literacy overall which is a measure of academic success. Improved education can lead to improved preventive care, improved access as well as advocacy. The right side of the causal loop looks more at tertiary care, as would be seen in a medical center environment. If treatment costs were lower, resources would be increased and more opportunities exist for prevention, access and advocacy. A less fragmented system (such as one based more in prevention and less on treating patients in "crisis") would result in a more optimal system of care.

10 Essential Public Health Services/National Goals Supported:



Our Change Master project supports many objectives related to diabetes as outlined in Healthy People 2020. This project looked at gaps in the education and care of people with diabetes related to income and education.

Specific objectives include:

HP2020-1 Increase the proportion of persons with diagnosed diabetes who receive formal diabetes education

HP 2020-2 Increase the proportion of adults with diabetes whose condition has been diagnosed.

HP 2020-3 Reduce the diabetes death rate

HP 2020-4 Reduce the rate of lower extremity amputations in persons with diabetes.

HP2020-5 Increase the proportion of persons with diabetes who obtain an annual urinary microalbumin measurement

HP 2020-6 Increase the proportion of adults with diabetes who have a Glycosylated hemoglobin measurement at least twice a year.

HP 2020-7 Increase the proportion of adults with diabetes who have an annual dilated eye examination

HP 2020-8 Increase the proportion of adults with diabetes who have at least an annual foot examination

HP 2020-9 Increase the proportion of persons with diabetes who have at least an annual dental examination

HP 2020-10 Increase the proportion of adults with diabetes who perform self-blood glucose-monitoring at least once daily

HP 2020-12 Reduce the death rate among the population with diabetes

- A. Reduce the rate of all-cause mortality among the population with diabetes
- B. Reduce the rate of cardiovascular disease mortality in persons with diabetes

HP 2020-13 Improve glycemic control among the population with diagnosed diabetes:

- A. Reduce the proportion of the diabetic population with A1C value > 9 percent
- B. Increase the proportion of the diabetic population with A1C value < 7 percent

HP 2020-14 Increase the proportion of the population with diagnosed diabetes Whose blood pressure is under control.

The project hopes to identify specific gaps in care and provide information that helps all those concerned about the status of diabetes in Kentucky improve services.

PROJECT OBJECTIVES/DESCRIPTION/DELIVERABLES:

The objectives of this project were to:

1. Gather data to help determine if there is a gap in prevention and treatment of diabetes in Kentucky between low income and other populations in Kentucky.

2. Utilize data to identify strategies to close existing gaps.

3. Increase awareness of the correlation between health and education and encourage stakeholders to consider reduced dropout and improved graduation rates as measures to improve health indicators in Kentucky.

After developing our feedback loop and evaluating the system, we concluded that it was possible and even beneficial to look at disparities in care from our diverse perspectives. We decided the resulting data can be useful for a variety of stakeholders who are interested in improving health outcomes for the state. We developed a survey for persons with diabetes who live in rural areas to complete. Data gathered from this survey will be available to diabetes groups across the state for use in program planning.

METHODOLOGY:

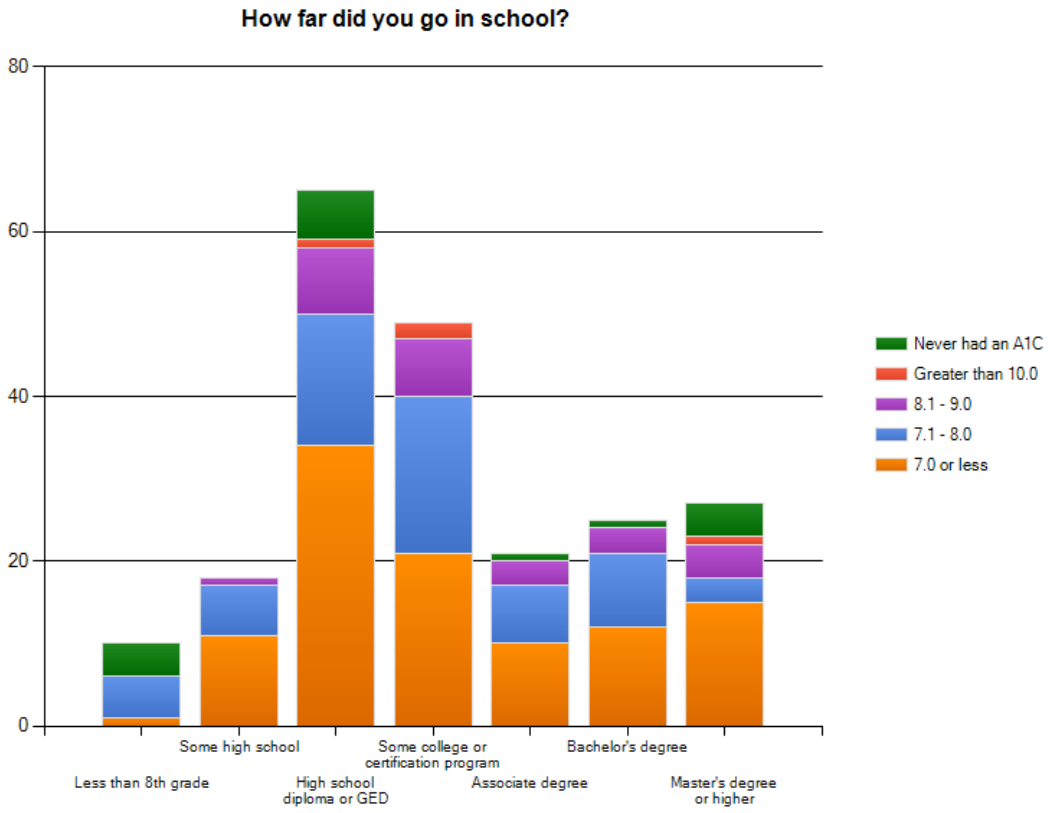
One of the most challenging aspects of our methodology was narrowing our focus. Our original focusing question targeted obesity as well as diabetes. Our original intent was to focus on the relationship between health literacy (or the lack thereof) and prevention and/or effective management of these diseases. We explored a wealth of information on health literacy, but we couldn't seem to identify a "deliverable" that we could produce. For various reasons, every idea we explored had some obstacle that we felt could not be overcome. Our work with systems thinking helped us redirect and focus on the gaps in prevention and treatment of patients with diabetes residing in rural areas in Kentucky and what causes those gaps.

Each of us had a very specific area of interest related to our focusing question and this was validated by our causal loop. While one team member's interest focused on the impact of high school dropout rates or limited education on diabetes prevention and management, the other team member's interest concerned the issues that limit access to care and resources people who live in rural areas may be experiencing. In order to blend these two perspectives, we decided to develop a survey and distribute it to our targeted population—people with diabetes that live in rural areas of Kentucky.

We developed a 24-question survey that we felt addressed the concerns of both team members. Working with our mentor, we obtained Institutional Review Board (IRB) approval for our research from the Cabinet for Health and Family Services (CHFS). Our relationship with Our Lady of Bellefonte Hospital enabled us to use Survey Monkey, one of the world's leading providers of web-based surveys. But, participants also had the option of completing the survey on a hard copy and returning it to us in a postage-paid envelope as Survey Monkey will allow the user to enter surveys manually. We asked diabetes educators, members of diabetes coalitions and

support groups, diabetes centers of excellence and local health departments (via the Department for Public Health) to help distribute the survey link. Both team members also visited a number of area diabetes support groups to ask for participant involvement and copies of surveys as well as the on-line link were left at one local pharmacy for people to be able to pick up as they obtained medications. Surveys were also sent to health ministry coordinators/faith community nurses in 56 churches in eastern Kentucky. It later occurred to us that it would be a good idea to share the survey with our KPHLI co-hort and the KPHLI leadership went a step further for us and even shared the survey with previous KPHLI co-horts. We hoped that each of us would be able to obtain 50 completed surveys for a total of 100. As we approached the collection of 100 surveys, we prayed for 150 surveys as we felt that was a more valid sample size. With the help of all of the groups previously mentioned, we now have 279 completed surveys and some amazing data.

Survey Monkey was a helpful tool for data analysis. In addition to tabulating each individual question, Survey Monkey has the capacity to cross-tabulate data for the user. The user selects one question to represent the control or independent variable. This might be a question such as age, gender, or education. Initially we chose A1C, a strong indicator of how well a person with diabetes is controlling his/her disease, as our independent variable. So, if we hypothesized that a diabetic patient with limited education will have a higher A1C, we can cross-reference our question about educational level with our control and obtain the following result:



In addition to A1C levels, we used questions such as age, gender, income level, and whether or not a patient had insurance as our control question(s) or independent variable, and cross-tabulated them with questions that addressed how well patients perceived they were controlling their diabetes, access to care issues, provider issues, their most challenging areas of self-care and how often they see their diabetes care provider.

RESULTS:

We initially targeted just the counties in which each team member lives and works. We identified diabetes coalitions, diabetes support groups, diabetes educators, local health departments, and churches as potential partners. But, as a result of getting the present and past KPHLI co-horts involved, we virtually covered the entire state (with the exception of Kentucky's urban centers of Lexington/Fayette County and Louisville/Jefferson County). This resulted in the collection of 279 surveys. We manually entered 190 of the surveys with only 89 participants completing the survey online.

Our response summary indicated the following:

- Nearly 75% of our respondents were female and over 65% of our respondents were over the age of 55 with the most surveys coming from the 55 to 64 years age bracket (34.4%).

- The educational level of most of our respondents was a high school diploma or GED with only 22.7% of respondents having a Bachelor's degree or higher.

- Seventy percent of our respondents had an income level of $40,000 per year or less. The most common annual income range was $10,000 - $25,000 and 22 respondents chose not to answer this question.

- There did not seem to be a correlation between income and reported A1C as a measure of diabetes treatment.

- Nearly 70% of respondents indicated their diabetes was found by their family doctor and 66.2% indicated they received education about their diabetes at the time of diagnosis. So, one-third of the people who took the survey did not receive adequate education at the time of their diagnosis—a huge gap.

- Nearly 90% of our respondents indicated they have health insurance but now we realize we did not design our survey question to show us whether respondents felt they had adequate coverage. Comments throughout the survey indicated that even though people had insurance, they still have to pay a lot of expenses in co-pays and medications. One of the most significant barriers we identified to people attending diabetes education programs was cost.

- Only 10% of our respondents were newly diagnosed (less than one year) diabetics. Most of the respondents had had diabetes between one and five years (31%) with an additional 50% falling between six and twenty years' duration. Only 8.1% of our respondents had had diabetes for more than 20 years.

- Eighty-one percent of our respondents indicated they had no difficulty finding a provider and 83.4% reported they drive their own car to appointments. Most of our respondents saw their provider every one to three months (46.5%). But 15% saw their doctor less than two times a year and an additional 7.6% only saw their provider when they felt like they needed to. Some of the reasons cited for infrequent provider visits were not having the money and having to travel too far.

- Only 23.8% of our respondents felt they were managing their diabetes well. The majority indicated they were managing their diabetes "fair" (40.7%) with 6.6% indicating they were managing their diabetes poorly. Interestingly, A1C levels were almost evenly distributed with 46.9% of respondents having an A1C

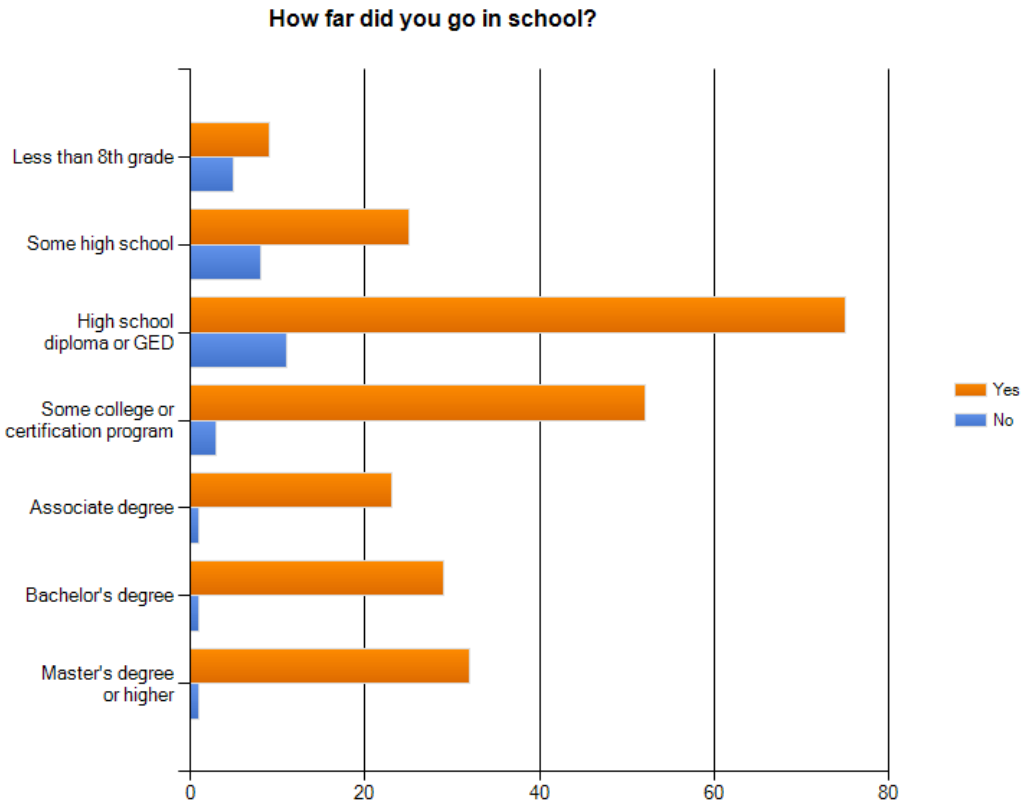
of 7.0 or less (good control) and 46% having A1C levels between 8.0 and 10.0 (fair to poor control). Over 7% of our respondents had never had an A1C which indicates another major gap in services.

- The aspects of diabetes self-care that our respondents found most challenging were exercising regularly (65.7%); following their diet (52.1%); and counting carbohydrates (44.1%).

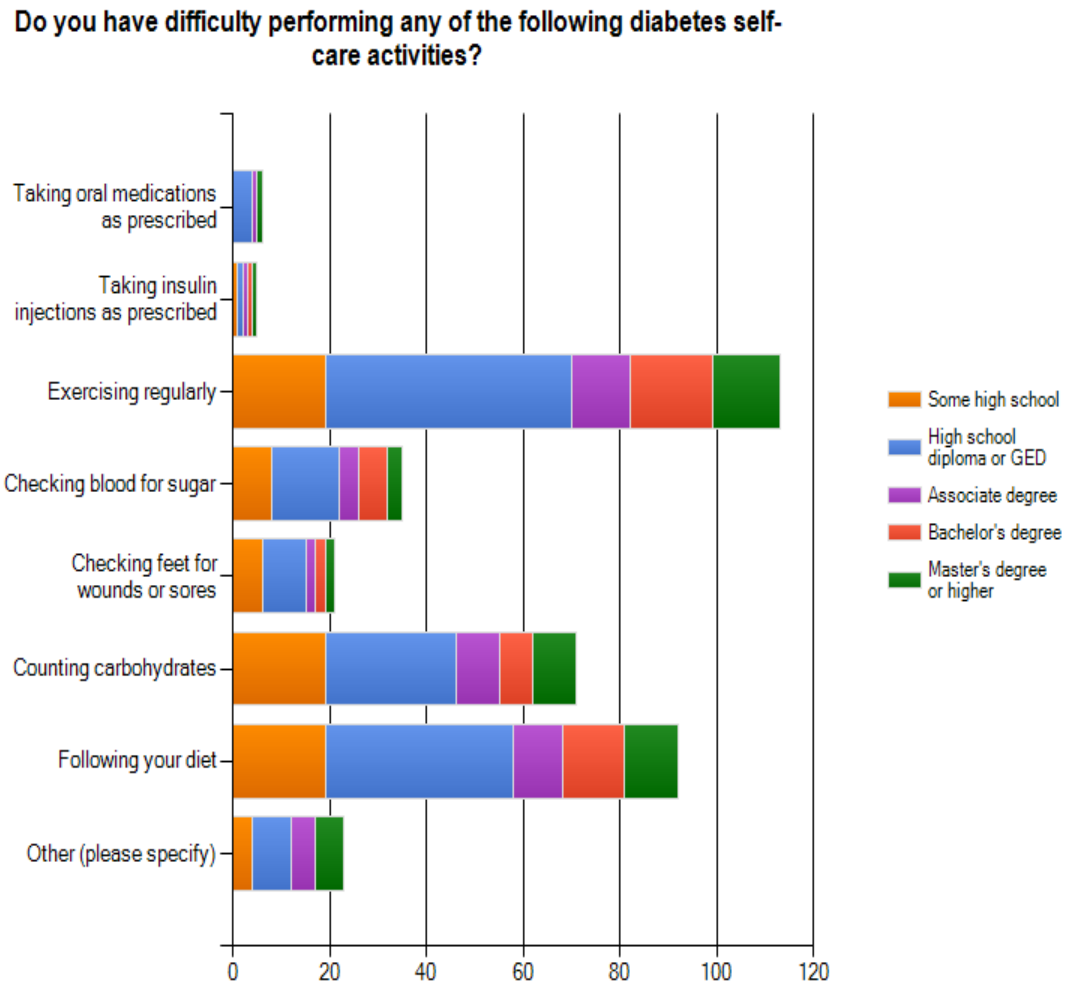
- Almost 12% of our respondents indicated there are no diabetes programs offered in their community. Taking this a step further, 68% of those that responded indicated they would attend such programs if they were free, at a convenient time and place, and they had transportation. Even some of the people that responded "no" to this question indicated they would come if these barriers could be resolved. Respondents also said they wanted up-to-date, current information at these classes—not the same old stuff they've been hearing for years. Only 8.6% of respondents preferred computer or internet-based diabetes education programs. Most (nearly 50%) preferred classes for groups held in the community that are free, at a convenient time, and do not require extended travel time. A little over 19% of respondents preferred one-on-one teaching sessions offered in the community. So, people want what we have to offer if it's free and convenient.

The next step in our project was to cross-tabulate some of this rich data. As we are new to research, we are finding this a daunting task. There are innumerable ways to cross-tabulate this data. We are actually still looking at this and plan to present our findings in greater detail when we do our project presentation. We will make those slides available to anyone that requests them at that time. But, basically, we chose to use A1C level, education level, gender, age, and income as our control variables and cross-reference those with questions that dealt with self-care, provider, whether the respondent has insurance, compliance and control. Here are some of our findings thus far:

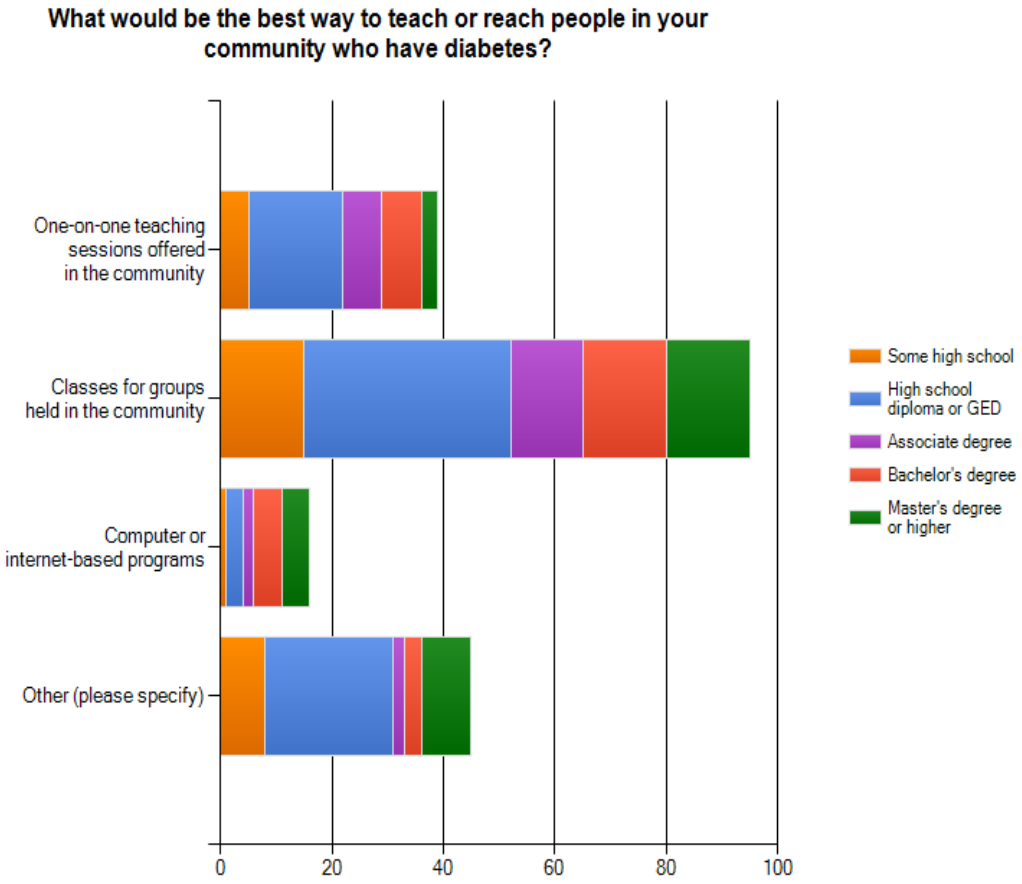
Not surprisingly we found a positive correlation between the level of education and whether or not people had health insurance:



But level of education did not appear to have a significant impact on the areas of self-care that respondents found most challenging. Regardless of the level of education, the areas of getting enough exercise, meal planning and counting carbohydrates were of most concern.



Regardless of educational level, most people felt the most effective way to assist people in communities with accessing diabetes programs and education was through group classes as indicated by the graph below:



It will take a significant amount of time to cross-tabulate each of these independent variables with the questions we feel will reveal the most information about where the gaps in services are occurring, but we have begun this process and we are excited about what we have identified thus far.

CONCLUSIONS:

We are extremely pleased with the response to our survey and the data obtained. As neither of us are researchers (yet), Survey Monkey was a tremendous help. Even though we thought we had designed simple, easy-to-understand questions, we quickly realized that some of our questions were confusing. Our "question design" was not always appropriate as some of the questions should have allowed multiple answers and we failed to accommodate that need. For example, many people checked more than one response to the question, "Who helps you most with managing your diabetes?" Since a significant number of our surveys were entered manually, we were able to somewhat compensate for that by checking the "other" answer and entering multiple answers in the comment section. But, people who took the survey online didn't have that option, so we didn't capture that data. And, although we do have the requested information in the "other/comments" box for surveys that were entered manually, it doesn't show up on the graphs and charts generated in the cross tabulation.

The data from respondents support these conclusions:

- People who live in rural areas are eager to participate in group classes in their community that are free, accessible, and offered at convenient times. They express interest in current, up-to-date information which will help them control their diabetes more effectively.
- There is a significant lack of awareness of the availability of resources in rural communities.
- There are a significant number of people in rural areas who have never had an A1C level checked (or if they have, they were not made aware of results).
- Many people with diabetes request opportunities to increase their physical activity and improve meal planning and carbohydrate-counting skills.

These findings offer a tremendous opportunity to begin the arduous task of developing programs addressing the root cause of some of these barriers.

We realize that there are many limitations to this data. The population sampled was in no way randomized and those participating in the survey were primarily people receiving support and/or care for their condition. They were motivated to seek assistance and education. Although we were pleased with nearly 300 respondents, that number in no way represents the experience of 324,000 adults with diabetes in the state. Chances are those falling into the "gaps" discussed were likely not those sampled.

Related to project objectives we can conclude that there are existing gaps in the prevention and treatment of diabetes in Kentucky. Some of those gaps were supported by this data. Gaps related to prevention, and the role education and school dropout can play in long term health outcomes were not clearly demonstrated but are worthy of continued investigation. This data can be used to close existing gaps and can be worthy information for agencies providing support and care for persons with diabetes.

NEXT STEPS:

We hope to continue studying this data and exploring the relationships we find. Certainly, we will share results with all of those who assisted us. We hope to develop resources that meet the needs expressed in some of the comments provided by the respondents and continue the work we have started. It is obvious from responses that there are many excellent programs existing in the Commonwealth that can use this information to grow as well and we can all look for root causes and ways to help stop the onset of this often preventable condition.

The final question of the survey asked, "What can we as health care providers do to make it possible for you to better manage your diabetes?" Our work was summarized and rewarded by the words of one respondent whose answer was simply, "Keep on caring". This charge is for all of us and reminds us of why we chose a profession in public health.

LEADERSHIP DEVELOPMENT OPPORTUNITIES:

Diana Williams

KPHLI has truly been an eye-opening experience for me. I have had the opportunity to participate in a 360 in the past, but the SocialStyle Self-Perception Profile and the Bar-On EQi self-assessment tools were new to me. One of the things they taught me is that I need to be willing to relinquish some control and ask for help. I have been practicing this at work with amazing results. Our work in systems thinking has helped me be more aware of the "big picture" which is a tremendous asset for a leader. I have really enjoyed working with Eva Stone, my partner in our change master project. I believe it was at Summit 2 that Eva and I realized we attended UK at the same time when we completed our master's in nursing, so it has been a joy to become reacquainted with Eva. I have also really enjoyed the opportunity to visit some of Kentucky's beautiful state parks for the first time. I love being part of the KPHLI community. I was amazed at the response we received when we asked not only our co-hort, but previous co-horts to assist us with distributing our surveys. It was truly a "community" response. I had not really had the opportunity to conduct research (other than our research class in our master's program) until KPHLI and I found that I really liked it. During KPHLI I have received recruiting information about UK's doctoral nursing programs and I found myself actually considering that during our project. I am very grateful to have had this opportunity.

Eva Stone

Participation in the Kentucky Public Health Leadership Institute has been an opportunity I have enjoyed. I have learned about myself – both strengths and weaknesses and I have learned more about working with others. I've been involved in a challenging project that I am glad my partner and I were able to participate in. We chose to tackle areas out of our normal comfort zone and although stress-producing at the time, helped us to learn and grow. I have recommended this institute to others I know who want to grow as leaders and hope to see the program continue to flourish.

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