

**Diabetes and the Rural Safety Net**

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## **EXECUTIVE SUMMARY**

**BACKGROUND:** The Institute of Medicine's report on America's Health Care Safety Net found it intact, but endangered, due to rising rates of uninsurance, and the erosion of subsidies. That report called for more in-depth study on special safety net issues for rural providers. A recent national study conducted by several rural health research centers found an intact rural safety net that addresses basic primary health care, but appears inadequate to meet the needs of persons with chronic illness, particularly diabetes, since rural prevalence is increasing. Compounding the higher rate of uninsured in rural areas is the greater reliance on high-deductible insurance in the individual insurance market, resulting in higher out-of-pocket costs for rural residents. This study investigates the extent to which the rural safety net is able to meet the needs of people with diabetes.

The safety net, both formal and informal, varies from community to community; though there are common features of this safety net amongst locales, the strength and degree of integration, the commitment of providers and organizations to the concept and philosophy of free or reduced care, and the degree of outreach to the population unable to pay for medical care are factors that influence the efficacy and strength of the safety net.

The formal safety net consists of providers that are government supported in full or in part, receive public subsidies to provide care to the poor and uninsured, or are obligated by law or regulation to provide care to people unable to pay. The informal safety net consists of private professionals and organizations that provide free and low-cost care to people unable to pay but who do not receive any public funds or other public support to compensate them for these services. Free and low-cost care is in the form of uncompensated care – charity and bad debt.

Diabetes is an example of an illness for which accepted protocols call for a number of services and supplies beyond the physician visit. These include frequent blood sugar tests, insulin (for those with Type I diabetes), regular visits to a podiatrist, and ophthalmologist, and nutritionist, and health education. Without proper treatment, a person with diabetes can develop secondary complications such as problems with the legs, feet, eyes, kidneys and heart.

**METHODS:** Data from the Behavioral Risk Factor Surveillance Survey aggregated for years 1996-97, are used to estimate the need for safety net services by rural diabetics. The analysis of national data, using SUDAAN software, compares small rural (less than 20,000), large rural (20,000-50,000), and urban counties using aggregated rural-urban continuum categories. The national data are supplemented with case studies of four uninsured or underinsured rural residents with diabetes from northern New England. The case studies draw on semi-structured interviews with four patients, and 24 providers, and state and local key informants.

#### **FINDINGS:**

**National Data:** Diabetes is more prevalent in small rural counties as compared to urban counties (5.54% vs. 4.85%  $p < .01$ ). Rural residents are at greater risk for Type 2 diabetes than those of urban counties, as indicated by rates of obesity, smoking, and exercise. Residents of small rural counties have a greater need for safety net services as indicated by higher rates of uninsurance (16% vs. 13.8%,  $p < .001$ ), lower household incomes ( $p < .001$ ) and by respondents who had delayed care due to cost ( $p < .001$ ). Diabetics in small rural counties are more likely to delay care due to cost than their urban counterparts ( $p < .001$ ), although they are no more likely to be uninsured.

**Case Studies:** Our case studies confirmed that some ongoing care currently recommended by the American Diabetes Association is delayed or forgone due to costs. A

variety of informal, often uncompensated, programs meet some of these needs. Safety net programs offered by pharmaceutical manufacturers are very helpful to those who qualify. However, we found that being insured was not a deterrent to significant out-of-pocket costs. One individually insured subject spends two-thirds of income on premiums and out-of-pocket costs.

## **DISCUSSION AND POLICY IMPLICATIONS:**

Small rural communities have a relatively greater need for safety net services to diabetics than their urban counterparts. To provide the needed array of services, medications, and support a coordinated, team approach to care is needed.

- ***Insurance coverage must be consistent with the standards of care.*** Since a major factor contributing to sub-optimal management of diabetes is the failure of insurers to cover all recommended continuing care, the strain on the safety net could be lessened by insisting that insurers including Medicare and Medicaid, modify definitional loopholes and utilization limits in order to follow the spirit of state mandates in payment for supplies, equipment, education, and prescription drugs.
- ***Facilitate team management and care coordination.*** To intensify the commitment to a team concept in diabetes care, partnerships between local public health workers, diabetes educators, and safety net providers must be encouraged. To facilitate team management, federal and state grant programs such as the community access program, rural hospital flexibility grants, and CDC grants targeted to diabetes, should require provider-to-provider networking and other team-building strategies as a condition for receiving funds. The CDC should also consider offering grants to state health departments to establish rural diabetes resource centers to centralize services, to equitably distribute specialists and technology, and

to disseminate information/education resources to clinical practices and patients alike.

- ***Formalize the informal safety net.*** Community-based mechanisms to formalize the delivery and coordination of free care and services are needed, with stable funding that is not totally dependent on private sector or foundation grants. Access programs are a step in the development of such mechanisms, but their dependence on grants raises questions about their sustainability. Formal safety net programs such as migrant and community health centers should be expanded, as planned by the current administration. In addition, states should encourage and facilitate the development of semi-formal safety net mechanisms like the Vermont Coalition of Clinics for the Uninsured.
- ***Further research is needed to better understand why rural residents are at greater risk for diabetes.*** Our finding, corroborated by other studies, that rural residents get less exercise, are more likely to smoke, and are more likely to be obese than their urban counterparts, is disturbing. One might hypothesize that the lack of sidewalks, bike paths and health clubs or the lack of dietary variety are contributing factors. Or one might argue that the lack of such amenities is a choice made in the context of a rural culture. A third hypothesis, supported by recent research on the social determinants of health would suggest that the lower socio-economic status of rural populations is a significant determinant of health behaviors.

# DIABETES AND THE RURAL SAFETY NET

## I. INTRODUCTION

In 1999, several Rural Health Research Centers collaborated on a project that sought to understand and quantify the rural informal safety net (RISN). Several products resulted from that collaboration, including case studies of eight rural communities and a preliminary report (Taylor, 2001). That project made a distinction between the formal safety net and the informal safety net. The former is defined as those health providers who are government supported, subsidized, or obligated to provide care to people unable to pay. The informal safety net includes private professionals and organizations who provide free and low-cost care to people unable to pay without benefit of subsidies or public funding.

As the rural informal safety net project was in process, the Institute of Medicine was working on a national report on the status of America's health care safety net (Lewin and Altman 2001). While the major findings of the IOM report focused on the effects of managed care and the rising number of uninsured, one key finding indirectly acknowledges the possibility that rural residents may find more holes in the safety net than their urban counterparts:

The patchwork of organization and the patchwork of funding of the safety net vary widely from community to community and the availability of care for the uninsured and other vulnerable populations increasingly depends on where they live. (p. 9)

One of the three sites visited by the IOM team was in rural North Carolina. Without devoting substantial time to unique rural issues, the authors acknowledged that "...vulnerable people in rural settings may rely more heavily on the commitment of local providers, such as private pay physicians' practices..." (Lewin and Altman 2001, p. 54.) The uneven distribution of formal safety net providers was one factor contributing to the design of the RISN project described above. Not only are federally-funded community health centers (CHCs) unevenly



distributed within states, they are dramatically underrepresented in many states, especially those in the Midwest.

A common theme of both the IOM report and the RISN project is a focus on primary care. It is generally hoped that adequate primary care has a potential to reduce the acuity of illness, reduce the probability of hospitalization, and, ultimately, reduce the cost of caring for vulnerable populations. However, as we interviewed primary care physicians and community leaders in these small rural communities, we were struck by a frequent theme voiced by providers: While many were willing to provide free or reduced-cost primary care visits, all expressed some difficulty in making referrals to specialty physicians, or to other services beyond the most basic of primary care needs. It appeared that the safety net story had not yet been told for an uninsured or underinsured rural resident with complex health problems. That was the impetus for this paper.

Diabetes is an example of an illness for which accepted protocols call for a number of services and supplies beyond the physician visit. These include frequent blood sugar tests, insulin (for those with Type I diabetes), regular visits to a podiatrist, and ophthalmologist, and nutritionist, and health education. Without proper treatment, a person with diabetes can develop secondary complications such as problems with the legs, feet, eyes, kidneys and heart (American Diabetes Association, 1998). In addition, diabetes is a widely prevalent health problem, with a higher prevalence in rural areas.

While rates of uninsurance are only slightly higher in rural areas, the proportion of the insured who purchase their insurance in the individual market is significantly higher in rural areas (Hartley et al. 1994, Shur and Franco 1999). Typically, these policies have poorer coverage than group policies, with higher deductibles and higher premiums (Hartley et al. 1994).

Because they are individually underwritten, those with chronic illnesses face even higher premiums. For example, a middle-aged male diabetic in Maine reported that he was offered an indemnity policy with a 20% coinsurance rate and a high deductible for \$600 per month. After paying such a premium, he would still face significant out-of-pocket costs (Douglass 1999).

Three factors may place rural residents at greater risk than urban residents for contracting diabetes, and for receiving inadequate care for diabetes. First, rural residents have been found to have higher incidence of smoking, and a more sedentary lifestyle (Eberhardt, Ingram, Makuc et al. 2001), both risk factors for Type II diabetes; second, the rural economy, characterized by lower wages and smaller businesses, has been shown to lead to more uninsured and underinsured people in rural areas (Hartley et al. 1994, Shur and Franco 1999); and third, as suggested by the studies cited above, the rural safety net tends to have fewer providers, and fewer resources from which to subsidize care for the indigent.

This project seeks to quantify these three factors, using data from a national survey, and to understand how this prevalent and costly illness is managed for rural patients who are uninsured or underinsured, using case studies and semi-structured interviews. Using national data from the Behavioral Risk Factor Surveillance System, we investigate urban-rural differences in the characteristics of persons with diabetes such as insurance status, income, and access indicators, as well as risk factors in the general population such as obesity, exercise and smoking. Four case studies of rural residents with diabetes in northern New England provide qualitative detail on the lives of these individuals and how they manage their illness.

## **II. BACKGROUND**

### ***Definition:***

Diabetes is a metabolic disorder, involving the interaction of insulin, a hormone produced by the pancreas, and glucose, a sugar by-product of the digestive process that serves as the

body's fuel. Without insulin, glucose stays in the blood and the cells basically starve. In Type I diabetes (often referred to as IDDM, insulin-dependent diabetes mellitus, or juvenile-onset diabetes) the pancreas stops producing insulin or produces an insufficient amount. In Type II diabetes (often referred to as NIDDM, non-insulin dependent diabetes mellitus), the insulin produced by the pancreas is not used properly; there is insulin resistance at the cellular level that inhibits the absorption of glucose from the blood. There are also "other specific types" in cases where specific genetic defects, surgery, drugs have caused hyperglycemia, and the fourth category is gestational diabetes mellitus (GDM), diabetes that develops during pregnancy. Diabetes can cause serious health complications including heart disease, blindness, kidney failure, and lower-extremity amputations.

About 7 percent of the adult population in the United States is affected by diabetes and 600,000 new cases per year are diagnosed (NIDDKD, 2000). On the average most people are not diagnosed with Type II diabetes until five to seven years after it has begun, by which time serious damage has occurred. The incidence has risen and the age of diagnosis has become younger (Tucker, 2000). About 16 million Americans have diabetes. Up to 800,000 people have Type I diabetes and more than 15 million people have Type II. An estimated 5 million people have Type II and do not know it. The people most at risk for Type II are over 45, overweight, sedentary and have a family history of diabetes.

### ***Care of Diabetes***

*Diabetes is a chronic illness that requires continuing medical care and education to prevent acute complications and to reduce the risk of long-term complications (ADA 2000).*

Current standards of care for diabetes call for screening, early detection, and individualized treatment plans which include continuing self-management training, regular and timely laboratory evaluations, medical nutrition therapy, appropriately prescribed medications, and monitoring, testing, and lifestyle modifications (exercise, weight loss programs, smoking cessation). Diabetes is a dynamic disease that demands daily attention and often requires

adjustments to treatment plans, including medications and diets. Patients need to monitor their own blood glucose levels daily, see a primary care provider 2-4 times a year for follow-up exams and testing, and visit a podiatrist and an ophthalmologist once a year for comprehensive evaluations. (See Appendix A for a summary of the American Diabetic Association's standards of Care.)

The "team approach" is an integral concept in achieving current ADA goals. "People with diabetes should receive their treatment and care from a physician-coordinated *team*. Such teams include, but are not limited to physicians, nurses, dietitians, and mental health professionals with expertise and a special interest in diabetes." ( ADA 2000) The collaborative model addresses the complex issues and requirements of the disease, the need for coordinated care from varied medical providers, and equal and active participation of the patient, as well as organizationally challenging providers' practices in the delivery of optimal care.

### ***Costs of Diabetes***

Individual medical costs of diabetes vary widely within the range of required services and prescribed medications; numbers of referrals to specialists in out-patient visits, the frequency of self-testing and lab work, the numbers, combinations, and dosage of insulin and/or oral medications for glycemic control and medications for control of other conditions differ from care plan to care plan. Annual costs of intensive therapy for people with IDDM (insulin-dependent diabetes) i.e., when either multiple daily injections or continuous subcutaneous insulin infusion are required, are greater than the costs to a patient with NIDDM (non-insulin dependent diabetes) who is controlling blood sugars with oral medications, diet, exercise, and daily testing. It is not unusual that a well-managed patient with NIDDM would be on 2-3 meds for glycemic controls, 2-3 for blood pressure, 2 for hyperlipidimia, 1 aspirin, a multivitamin, and HRT (hormone replacement therapy) (Interview with physician and RN/CDE).

Furthermore, the marketplace holds a considerable cost range for medications and durable goods. Newer medications such as Avandia are far more expensive than the generic of a drug that may have been on the market longer. A month's supply of Avandia 4mg taken twice a day can cost \$174.69 whereas the generic of Micronase (Glyburide) 5mg taken twice a day can be purchased from the same pharmacy for \$31.98. Technologically advanced glucose testing and insulin-delivery equipment, such as the audio glucometer and the infusion pump, is continually being developed for patients who are visually impaired, have poor coordination, or who are "on the go." However, the increased costs associated with new technology are not automatically covered by insurance. Data management software, monitors that measure multiple blood values (cholesterol, ketones, triglycerides, HDL as well as glucose), and home kits for measuring A1C levels are all innovations that may elevate the capacity of patients with diabetes to self-manage, but their availability and affordability may limit them to a upper economic stratum of the population with diabetes.

In the Diabetes Control and Complications Trial (DCCT), the annual cost of intensive therapy (\$4,000 and \$5,800/year for multiple daily injections and continuous subcutaneous insulin infusion, respectively) was approximately three times the costs of conventional therapy (\$1,700/year). A large portion of the difference in cost was related to the greater frequency of outpatient visits and the greater resources used in self-care (ADA, Diabetes Care Vol 18. Nov. 1995). Though these figures are not current, they indicate a relevant comparison between the IDDM and NIDDM patients. Currently, both the ADA and the CDC estimate that a person with diabetes will spend between \$10-12,000 per year on medical care. (For a chart summarizing the costs of diabetes care, see Appendix B.)

## ***Diabetes and Insurance***

Since therapy for diabetes requires substantial use of health services and supplies, inadequate insurance coverage may impede access to such care and adversely affect health outcomes. Lorenzi et al examined the relationship between insurance coverage, health outcomes, and the characteristics of persons with Type I diabetes with non-continuous insurance (Lorenzi 2000). They concluded that non-continuous insurance coverage is a barrier to implementation of intensive therapy and adversely affects levels of glycemic control. Ettaro et al. also have studied this relationship; their data demonstrate that “insurance influences the use of diabetes services, glycemic control, and AER [albumin excretion rate] over the long term. There is some indication that insurance also affects the development of the long term complications of Type 1 diabetes” ( Ettaro et al, 2000).

### *Limitations of Insurance:*

As absence of insurance inhibits access and delivery of care, so do the limitations imposed by state regulations and insurance contracts. Despite the fact that Maine, New Hampshire and Vermont all have legislation mandating 3rd party reimbursement for diabetes education, equipment and supplies, *definitional loopholes and utilization limitations* in the laws, regulations and/or particular insurance policies or contracts protect some third parties from making payment, resulting in inadequate coverage for many of the insured. For example, in Maine, insurers are mandated to pay only for education which is provided by “facilities authorized by the State’s DCP within the Bureau of Health.” Medicare regulations have also placed stipulations on diabetes educators, allowing payment only for certain educators in certain facilities. Similarly, Medicaid’s utilization limits on the monthly allowance of strips and syringes can place undue strain on people with diabetes.

Non-coverage of prescription drugs is a significant limitation of insurance. Medications are a major component in the care plan for people with diabetes; not only are insulin and oral agents for glycemic control required, but medications for the co-existing complications of diabetes, such as hypertension, high cholesterol, and cardiac conditions are common in care

plans. Therefore, expenditures for medications are a constant and significant budgetary consideration in the management of this chronic disease. Medicare does not cover outpatient prescription drugs. Although 69% of Medicare beneficiaries had drug coverage for at least one month in 1996, only slightly more than half (53%) were covered for the entire year. Almost a third (31%) of Medicare beneficiaries had no drug coverage in 1996 (Kaiser Family Foundation, 2000). A recent study found that rural elders were significantly less likely to have prescription drug coverage than their urban counterparts, and had significantly higher out of pocket drug costs (Coburn and Ziller 2001).

### ***The Safety Net***

Safety net providers are those professionals and institutions that provide care to the poor and uninsured. For purposes of this study, the formal safety net consists of providers that are government supported in full or in part, receive public subsidies to provide care to the poor and uninsured, or are obligated by law or regulation to provide care to people unable to pay. The informal safety net consists of private professionals and organizations who provide free and low-cost care to people unable to pay but who do not receive any public funds or other public support to compensate them for these services (Adapted from Ricketts, et al., 1998). Free and low-cost care is in the form of uncompensated care – charity and bad debt.

The safety net, both formal and informal, varies from community to community; though there are common features of this safety net amongst locales, the strength and degree of integration, the commitment of providers and organizations to the concept and philosophy of free or reduced care, and the degree of outreach to the population unable to pay for medical care are factors that influence the efficacy and strength of the safety net.

### ***Medical Providers' Role in the Informal Safety Net:***

Providers are involved by committing philosophically to public health and the concept that the inability to pay should not prohibit an individual's access to medical care; by administering contributions of time, money, medicines, equipment from individuals, community groups, corporations, and foundations; by sacrificing financially with reduced fees or free care;

and by advocating for changes in legislation and policy related to costs and payment of medical care.

Though, for the most part, the informal safety net functions idiosyncratically in geographical pockets and/or in reaction to particular individuals and situations, there are examples in New England of "formalizing" the informal safety net.

*Access Programs:*

In New Hampshire and Maine, several access programs currently serve the un/underinsured, in both rural and urban settings. The goal of these programs is to increase access to care and close gaps in service delivery through community-based networks of providers donating services in their facilities. Eligible individuals must meet income criteria in order to qualify for a "membership card" which secures access to the network. Preventive and primary care and education are emphasized. Referrals to specialists are made within the network of participating providers. Hospital care, limited prescription coverage, and lab work are available. There are zero or low co-pays. A case manager enrolls members, assists them in connecting with other appropriate human service resources, and acts as a liaison between enrollees and providers' offices, thus alleviating administrative burdens to providers. An excellent example of an access program operating in New England is the Healthlink program developed by Lakes Region General Hospital in Laconia, New Hampshire.

These programs have been established with input from physician groups, hospitals, state and local governments, advocacy groups, insurers and businesses; foundation funding and hospital contributions are primary funding sources. Concerted outreach to target populations is essential to effective utilization. Equally important is the willingness of providers and funders to participate.

*Free Clinics:*

Though each free clinic has its unique operational style, there are features which distinguish them within the informal safety net. Clinics are usually established in response to community concern about area residents not being able to afford health care. They are staffed by



rotating volunteer health care providers (including but not limited to physicians, nurse-practitioners, physician assistants, nurses, pharmacists, psychologists, nutritionists) as well as other community members. Local hospitals donate vouchers for laboratory, x-rays, and ancillary care. Some clinics are programs with local hospitals and are staffed by hospital employed health care providers. Unlike access programs, however, in which patients are seen within the office practice setting of the provider, free clinics are free standing or use donated space of a local physician, organization or hospital, often in evening hours. Operating costs are covered in a variety of ways - local fund raising, foundation grants, patient donations, hospital contributions, state and Federal monies. Operating costs can cover salaries of coordinator, case manager, office expenses, and most clinics also maintain a “slush” fund to help cover medications, medical bills of referral providers who will take referrals from the clinics but require some form of payment.

Free clinics and access programs serve a population of uninsured who either fall between the eligibility cracks of state and Federal programs, the working poor and in some cases those whose incomes are relatively high but who are uninsured because employment-based insurance has been terminated.

#### *Support Groups:*

Support groups can be social, educational, and psychologically therapeutic forums for individuals living with a specific health issue. In this study, both patients and providers referenced support groups as an important part of the informal safety net, specifically noting that such groups 1) offer positive re-enforcement of self-management skills, 2) provide free and continuing education from volunteer professionals who facilitate the groups or guest lecture, and 3) encourage the team approach in patients and providers outside of the clinical setting.

#### *Screenings:*

Free screening sponsored by area hospitals and community organizations are pro-active preventative measures that serve as educational outreach and also capture and engage affected populations.

#### *Pharmaceutical Companies' Role in the Informal Safety Net:*

Prescription medications and supplies are a significant component in managing diabetes and its complications. For the under or uninsured, procuring the often multiple medications and the supplies for daily testing and insulin administration (strips and syringes for example) can be difficult. Pharmaceutical companies are players in the informal safety net by dispensing free products. Company representatives historically have dispensed samples as marketing tools to physicians and diabetes educators, who then pass them on to patients in offices, classes and clinics. Additionally, several major pharmaceutical companies have established prescription assistance programs to provide medication free of charge to those who are in financial need. Each company has its own eligibility standards, application procedures, and duration of service (Pharmaceutical Research and Manufacturers 1999-2000). Patients must access these programs through their doctors' offices who coordinate the paperwork for the patient and receive and dispense the drugs. For example, in 1996, 26,000 people with diabetes were enrolled in Eli Lilly's patient assistance program, Lilly Cares. That year, the company donated \$5 million worth of insulin to the program. (D'Arrigo 1998)

*Foundation Funding of the Informal Safety Net:*

Foundation funding of health initiatives is playing an important role in providing care to the un/underinsured. An example of underwriting the informal safety net can be seen in the Robert Wood Johnson Foundation's "Communities in Charge: Financing and Delivering Healthcare to the Uninsured" which has given start-up money to access programs in New England to encourage volunteer services from physicians. The United Way and several more regional and local foundations in New England are also supporting the informal safety net with donations to free clinics and access programs. Expectations of continuous and adequate aid to the informal safety from the foundation sector may be unrealistic, given the reality that foundation support is contingent on funding cycles, or is often earmarked for start-up, outreach, capacity building instead not for direct services.

*Community Organizations in the Informal Safety Net:*

Well-known organizations such as Kiwanis, Rotary and Lions often offer health-related

programs in their communities such as funding to purchase glasses.

### **III. METHODS**

This study examines three sources of data to determine the extent to which the rural safety net is meeting the needs of people with diabetes. For the national perspective we use aggregated data from 1996 and 1997 from the Center for Disease Control's Behavioral Risk Factor Surveillance Survey (BRFSS) to conduct urban-rural comparisons of risk factors for diabetes, household income, insurance status, and delayed care. For these analyses, we use a three-level indicator of rurality, with rural respondents classified into two groups, based on whether their community is a "small rural" community (less than 20,000) or a large rural community (20,000 - 50,000). SUDAAN software was used to adjust for sampling probabilities.

Two types of primary qualitative data were gathered from regional sources. First, we conducted 24 semi-structured interviews with key informants in Maine, New Hampshire and Vermont, including providers, administrators, and care coordinators to determine the types of services offered, available resources (funds and supplies), best practices and problems or unmet needs. These interviews used the methodology developed for the RISN project described in the introduction (Taylor et al.2001). Table 1 presents a list of the key informants interviewed.

In addition, we interviewed four persons with diabetes residing in rural Maine, New Hampshire and Vermont who were identified by the key informants. These interviews focused on available free or reduced-cost care, out-of-pocket costs, and complications or other health problems. The four case studies provide a means to understand how various personal, ecological and policy factors interact at the individual level to help or hinder the provision of ADA-level care

## **Table 1** **Interviewees**

Twelve (12) providers with a range of responsibilities:

- Board Certified Orthopedic surgeon/Medical Director of a free clinic,
- Board Certified Endocrinologist with a specialty in diabetes,
- RN/CDE (certified diabetes educator) in community hospital,
- ARNP(nurse practitioner)/(CDE) focusing on diabetes in a family practice,
- RN/Case Manager in a free clinic,
- RN/CDE statewide educator,
- RD(registered dietitian)/CDE in community hospital,
- RN/designated “diabetes nurse” in home health agency,
- RN in family practice, formerly CDE in tertiary hospital
- Non-practicing RN managing volunteer community health association,
- Pharmacist for large chain pharmacy in small community,
- Social Worker at FQHC.

Nine (9) administrators:

- Three top administrators of each State’s Diabetes Control Projects,
- One director of community relations at a community hospital,
- One volunteer citizen who manages a Kiwanis Club-sponsored free clinic,
- Two directors of county extension services,
- Two coordinators two access programs in Maine.

Two (2) regional directors of non-governmental organizations (United Way and American Diabetes Assoc.),

One (1) field representative from a major pharmaceutical company, and

Four (4) people with diabetes were interviewed.

## **IV. FINDINGS**

### ***National***

According to the BRFSS, Diabetes is more prevalent in small rural counties as compared to urban counties (5.54% vs. 4.85%  $p < .01$ ). Rural residents are at greater risk for Type 2 diabetes than those of urban counties, as indicated by rates of obesity, smoking, and exercise (Table 2). We also used general health status as a risk factor, and found that small rural residents were more likely to rate their health fair or poor than urban residents. Figure 1 illustrates the relatively greater risk of respondents from small rural counties.

Residents of small rural counties have a greater need for safety net services as indicated by higher rates of uninsurance (16% vs. 13.8%,  $p < .001$ ), lower household incomes ( $p < .001$ ) and by the percentage of respondents who had delayed care due to cost ( $p < .001$ ). These

findings are shown in Table 2. Figure 2 illustrates the disadvantages for small rural residents. Note that in all cases, large rural counties fell between the extremes of small rural and urban, suggesting that rurality is a continuum, and that an ordinal, rather than a dichotomous indicator of rurality is appropriate.

Among the subsample of respondents with diabetes, we found that those in small rural counties are more likely to delay care due to cost than their urban counterparts ( $p < .001$ ), although they are no more likely to be uninsured (Table 3).

**Table 2**  
**Risk Factors for Diabetes and Need for Safety Net<sup>a</sup>**

	<b>Small rural &lt; 20,000 (n=53,867)</b>	<b>Large rural 20,000-49,999 (n=24,854)</b>	<b>Urban &gt; 50,000 (n=161,044)</b>	<b>Total (n=239,765)</b>
<b>With diabetes<sup>b</sup></b>	5.54	4.75	4.85	4.94
<b>Obese<sup>c</sup></b>	39.5	36.0	34.2	35.1
<b>Smoke<sup>d</sup></b>	24.9	24.6	22.9	23.3
<b>Inadequate<sup>e</sup> exercise</b>	63.1	58.1	57.5	58.3
<b>Health status fair or poor</b>	18.4	14.3	13.4	14.1
<b>No health insurance</b>	16.0	14.2	13.9	14.2
<b>Income &lt;\$25K</b>	42.9	37.8	31.5	33.5
<b>Delayed care due to cost</b>	12.3	11.6	10.6	10.9

a. Percent of sample

b. Excludes gestational diabetes

c. A body mass index greater than 120% of the mean

d. Survey question: "Do you smoke now?"

e. Adequate exercise is considered to be at least three times a week for 20 minutes or more.

Note: All urban vs. small rural differences are significant at  $p < .001$  based on chi-square

**Table 3.**  
**Characteristics of Urban and Rural Residents with Diabetes**

	Small rural < 20,000 (n=3077)	Large rural 20,000-49,999 (n=1174)	Urban > 50,000 (n=8018)	Total (n=12,269)
<b>No health insurance</b>	10.2	10.4	10.0	10.0
<b>Delayed care due to cost</b>	15.7 *	12.9	11.8	12.5

\* urban-small rural difference significant at  $p < .005$  based on chi-square

***Northern New England Case Studies***

We interviewed four persons with diabetes who were identified by providers as either uninsured or underinsured, 2 men/2 women, 2 married/2 single, were all Caucasian, over 45 years old, obese, diagnosed with Type II diabetes, living in towns with less than 1000 people. The two married individuals had the highest household incomes (\$30,000 and 22,500) while the single individuals' income ranged between \$6700 and \$11,250. Four different insurance profiles were seen in the subjects - no insurance, Medicaid coverage, Medicare coverage, and private insurance. Meeting medical costs presented difficulties for all four subjects. Each subject carries the physical, psychological and economic burdens of diabetes with varying degrees of success, understanding and acceptance. Each subject's story sheds light on aspects of the delivery of diabetes care and how the informal safety net serves the under/uninsured person with diabetes in rural New England.

**Subject A:** Subject A is a 54 year old married male living with his wife and her 28 year old son by a previous marriage, who, coincidentally, suffers from fairly severe complications of Type I diabetes. They own their home and surrounding acreage in a farming community in Vermont of approximately 400 people, 15 miles south of a hospital and the free clinic they attend. Both own and drive cars. Subject A was once employed and insured by a training school for mentally retarded children in a neighboring town, then by the highway department; he is now employed part-time delivering newspapers on a local route. He takes home \$109/wk

from this job. His wife is currently unemployed, though she was previously a medical secretary, employed and insured. In 1995, Subject A received an inheritance from which he draws \$1050/month; their investment counselor has advised that they both find employment in order to protect funds for their retirement. Subject A is looking for work using his training in electrical services. They also derive about \$4300 per year from selling hay and honey comb. Their net income is approximately \$22,600.

Until about a year ago, Subject A had a health insurance policy with a \$5000 deductible for each of the couple, no coverage of doctors' visits, partial coverage of prescriptions (after a \$100 yearly deductible) and of lab work. They discontinued this policy when the premium increased from \$227/month to \$275/month (\$3300/yr) and they decided that the benefits did not justify the cost. At the time of this interview Subject A and his wife were not eligible to apply for VHAP (Vermont Health Access Plan) because they had not been without insurance for a full year. They were also uncertain whether they would meet income criteria. The free clinic will assist them with the application if and when appropriate.

Subject A was diagnosed with "borderline" diabetes several years ago at a family practice in a neighboring town and was told that it wasn't serious enough to warrant treatment or follow-up. Subject A was obese, had a history of hypertension, kidney stones, and a family history of diabetes and heart disease. Concerned about "some urinary difficulties," he presented at the free clinic in 1999 where the diagnosis of diabetes was confirmed. Since that time the clinic's nurse/case manager and providers have treated him in accordance with the standard of care; including exams every three months, foot exams, lab work (A1C, urine). The clinic also provided him with a free glucometer, testing supplies, sample medications, and enrolled him in a pharmaceutical patient assistance program.

The interview with Subject A and his wife keyed in on the following themes:

*Total Dependence on the Informal Safety Net:* Subject A depends totally on the free clinic for his health care. "If [the free clinic] wasn't there we would neglect our health. I think we would just not go to the doctor, unless we were really sick or something bad happened."

The couple's out of pocket expenditures for medical costs are minimal at this point, since the free clinic covers primary care at the free clinic, specialist referrals and labs with vouchers, and medications with samples and participation in the pharmaceutical company drug programs. The Clinic also got the Lions' Club to donate a hearing aid to Subject A. Their largest medical expense is monthly payments for past bills (\$75/month). Adding miscellaneous items such as vitamins, skin products and the wife's bills, Subject A and his wife pay about 6% of their net income for out of pocket medical expenses.

*Stress Accompanying Chronic Illness:* Subject A's wife was more voluble than her husband in expressing anxiety, acknowledging that her fear about diabetes was partially due to her son's complications. Subject A also expressed some anxiety, indicating that having a chronic illness "could make you nervous." Furthermore, the process of aging in conjunction with a chronic illness is worrisome, particularly without a means to pay for medical services. "Wife: You get more frightened not to have health insurance as you get older. Husband: Because you just don't have the health."

*"Denialbetes":* Subject A does not believe any serious complications will result from his diabetes if he keeps his sugar down. "I don't think I have any major problems; it doesn't seem like I do; maybe I do and it's something I don't know about." However, Subject A offers that he gave up self-testing procedures because it made his "fingers sore and I was getting about the same readings all the time so I didn't think it was really necessary." His feet bother him "a little, and "only once in awhile feels the tingling," but he doesn't believe he has neuropathy. He and his wife are "just hoping nothing else serious happens before we get eligible for Medicare." Subject A's denial of the possible consequences of his illness appears to affect his medical decision-making and his attitude toward self-management, as does his economic status.

*Ability to Pay Affecting Self-esteem and Medical Decisions:* Subject A and his wife repeatedly expressed their feeling that lack of money can undermine self-respect and a sense of self-sufficiency, and that the inability to pay for care can influence medical decision-making. In speaking of the clinic, "We thought you'd have to pay something. We thought it would be too



good to be true that you actually go without having to pay. They treat you with dignity and respect even though you don't have money, and that was very important. It's been a godsend really."

**Subject B:** Subject B is a 57 year old married female, living with her husband and one of two grown children, in their own home in a New Hampshire town with a population of 200, approximately 15 miles from the community hospital and her family practice. Subject B has not worked for 10 years; she receives workman's compensation (indemnity and medical) for a shoulder injury she sustained at work 10 years ago. She also has received Social Security Disability, and therefore Medicare, for the last 7 years. Her husband works in maintenance at a local resort and carries no health insurance. Both Subject B and her husband own cars; she, however, does not drive at night due to bad night vision.

Subject B receives approximately \$15,000, combined from Social Security Disability and Workman's Comp benefits; her husband adds \$15,000 to the household income. Out of pocket medical expenses (\$5100) account for approximately 17% of total gross income, inclusive of co-pays, and \$2400 for medications not covered by Medicare. Her out of pocket medication costs decreased from \$500 to \$200 per month once her nurse practitioner enrolled her in a pharmaceutical company patient assistance program. Her out of pocket costs for testing supplies decreased considerably when she discovered from a support group member a mail order company in Florida that markets to people with diabetes on Medicare.

Subject B describes herself as "basically healthy" despite the chronic conditions of diabetes, a "bad" knee, back and shoulder. She has been told she will need replacement surgery on both her knee and shoulder. She was diagnosed with diabetes three years ago after sustaining a severe infection for which she was hospitalized. She has been seen for her diabetes since that time by a nurse practitioner at a family practice. Her diabetes is kept under control with oral agents (she was previously on insulin), careful dietary planning and a daily walk; she feels confidence in her caregivers, follows the established care plan designed in conjunction with her nurse practitioner who specializes in diabetes care, and is very motivated in her self-

management.

Subject B worries about getting older with her chronic disease and concurrent orthopedic conditions, living on a fixed income and facing increased medical costs particularly for medications. Though she will seek medical care if she needs it, she wants to avoid her orthopedic surgeries as long as she can because even with Medicare paying 80% of many of the bills, the balance of surgical costs would be very difficult to handle. She also has no idea of what would happen if her now-healthy husband developed a medical condition or had a serious accident. She and her husband have consciously devised budgetary strategies to get by, but medical expenditures are a continual and pressing demand. “We do whatever we have to.”

Subject B highlighted the importance of:

*The Informal Safety Net as an Integral Part of Self-Management--Support groups:* Not only does Subject B value the social networking of her group who share recipes, personal experiences with diabetes, and information about diabetes products and medications, but also the free education about her disease brought to the group by a variety of medical providers such as an endocrinologist, ophthalmologist, and dietitian, who volunteer their time at no cost to the group.

*Drug Assistance Programs:* Subject B saves approximately \$3600 a year in out-of-pocket expenses for medications since her nurse practitioner enrolled her in pharmaceutical company programs. These two examples of the informal safety net are vital to Subject B’s financial and physical well-being.

*Incentive to Self-manage:* Having had an aunt who went blind and lost a foot due to diabetes has given Subject B the “incentive” to meet her diabetes head on: “I know what can happen so I know what I have to do and I do it.”

*Caring & Knowledgeable Primary Care Giver/Case Manager:* Working with her nurse practitioner who is “an expert on diabetes” is vital to Subject B’s active involvement in her treatment plan: “I wouldn’t trade her for anybody. She may not be a doctor but she’s amazing.

She's got 3 or 4 doctors who back her up if need be, but I swear by her; she is much more compassionate than most doctors and spends time with me." She doesn't know what she would do without her nurse practitioner's help, medically, psychologically or financially.

*Continuing Education:* Subject B feels there is always something new to learn and that a one time diabetes education class is not necessarily sufficient for people with diabetes. Not only has her nurse practitioner offered her diabetes education, she has also provided her access to a free support group and continuing and practical education.

*Family Support:* Subject B's husband, the cook in the family, is diligent about preparing appropriate meals. Though he does not attend the support group nighttime meetings, he faithfully transports his wife and always wants her to share what she learned with him. Subject B says having support from everybody in the family makes it easier for her to accept and manage her disease.<sup>1</sup>

**Subject C:** Subject C is a 57 year old, unemployed, divorced man. He lives alone in a town of 800 people in Maine. His ex-wife, two grown children and grandchildren live within six miles, but are not a part of his everyday life. He lives approximately 20 miles from his hospital and medical providers. He owns a home and a vehicle. He has an individual health insurance policy with Anthem/Blue Cross Blue Shield.

Subject C suffered a head injury after a serious motorcycle accident in 1989 and had to leave his job as a limousine driver. In 1990, after his first heart attack, he moved to Maine. Receiving \$1200/month from an annuity obtained from the settlement of the accident, he remained unemployed until early 1995 when he established a cleaning business which he subsequently had to give up because the work was too physically demanding. He is currently unemployed.

Subject C was diagnosed with diabetes in the early '80's and understands the seriousness of monitoring his disease. At the present time, his diabetes is treated with oral agents. He tests

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<sup>1</sup> When families are involved in the regimen, patients are more likely to take meds and follow proper diet (AHCPR, 1999)

his blood sugars daily, sees his primary care provider regularly every three months for foot checks, lab work (including A1C), and the ophthalmologist every six months for eye exams; he states he would see the cardiologist only if there was a problem or if his PCP referred him, but does not have regularly scheduled visits. Having been obese for many years, weight loss is a prime concern: he realizes this is a vital component of the “discipline” of self-management, but wishes he had more help with “actual menu plans” because he finds it difficult to manage his diet and weight.

Subject C’s available funds are derived from his annuity from which he is allowed to draw \$12,500 a year; after taxes this results in \$11,250. The value of the annuity will decrease in principal value since he is annually drawing out funds. He uses this money to make payments on his credit cards to which he charges all daily living expenses. He charges up to the credit limit of the cards each year, and monthly payments increase as the year progresses. His American Express card has a credit limit of \$17,000 @ 12.99% interest; his Discover card has an \$11,000 limit @ 21% interest. He has no other income. After a second heart attack in 1998; he applied for Social Security disability which he did not receive because he fell short of the number of work-quarters required. He is not eligible for SSI, food stamps or Medicaid because of the value of his annuity and vehicle.

The interview with Subject C illustrated the following:

*“Insured” Does Not Necessarily Mean “Covered”*: Subject C feels he is constantly “behind the 8 Ball” financially, and his health status is a driving force behind financial decisions. Having health insurance is a major priority to Subject C, and he forgoes other things in his life in order to retain insurance. When Subject C moved to Maine, he had a “top of the line” policy, BC/BS Medallion, which he retained for 18 months under COBRA; he then signed on with BC/BS Health Choice (now Anthem). He pays cash for medical services then submits claims for reimbursement, a process which adds to his irregular cash flow. In addition, he is often unsure whether claims will be covered and if he will have to deal with the insurance company. The \$479/month premium comprises a major portion of his budget. In addition to the \$5,748/year he

spends on insurance, he spends approximately another \$1500 out-of-pocket for co-payments, the deductible, past medical bills to his cardiologist. Subject C spends close to 2/3 of his available annual funds for medical costs. When confronted with this fact during the interview, Subject C expressed surprise; he “had never thought of it that way.” Even though he has private insurance, the economics of his health care remain constantly stressful. Though he has prioritized medical spending in his budget, it is still difficult for Subject C to cover all of the goods and services medically indicated.

*Inability to Pay Affects Medical Decisions:* His insurance will not cover the diabetes education at his hospital because it is not part of the State’s education program, and though he states he needs more counseling from a dietitian he feels he cannot afford it. He also forgoes dental care though his teeth need attention, sleeping pills though he cannot sleep, and a new lens prescription because he feels he cannot afford these items. He stopped his cardiac rehab when his insurance coverage ceased at 8 weeks. He then went to a cardiac rehab program sponsored by the hospital at the YMCA where he was given a “scholarship membership”, a \$300 fee reduced to \$120 (YMCA gets “scholarship” funding from United Way). However, once the price of gas started rising he stopped making the 30 mile round trip.

*Limited Use of the Informal Safety Net:* He uses the food bank at a local church once a month to help with his grocery bill. He knows there is a diabetes support group in his area but he has not “taken the time” to attend despite the fact that the support group may offer free education; now with high gas prices it is definitely not a consideration. The hospital has written off several hundred dollars past due balances. The informal safety net, including hospital write-offs, the reduced fee at the YMCA, and the food bank, has saved Subject C hundreds of dollars over the last two years. He has made use of the informal safety net when it was offered, but, he does not rely on or seek out resources in the community that may be of assistance in the financial planning of his medical care. Of note, Subject C’s diabetes educator interviewed for this study stated that she did not think the informal safety net in her area existed to any meaningful extent, that it was “something that needs more investigating.” Subject C’s limited use of the informal

safety net reflects both patient reticence and the absence of a strong informal safety net in his area.

Subject C has limited financial resources, but his unique financial situation places him outside of the formal safety net. Furthermore, his approach to managing his resources combined with his commitment to retaining a high-cost insurance policy exerts strains on his cash flow. Subject C illustrates that being “insurance rich” in and of itself does not necessarily ensure complete coverage of medical needs, optimal health or peace of mind without other economic safeguards in place.

*Mental Health Implications of Chronic Disease:* Subject C does not believe he is “depressed” but acknowledges that he is “nervous and anxious” about his chronic medical condition, especially the possibility of further heart attacks. He has a hard time seeing how he will manage in the future and would rather not think about it. He wishes his children were more interested in his condition and involved in his daily life. He states that the combination of his financial situation and his physical condition is a constant stress.

**Subject D:** is a 55 year old single woman living alone in her own home in Maine, in a town with a population of 200. Of the four subjects, she has the fewest financial resources and is the most debilitated by her diabetes. In addition to hypertension, obesity, cardiac compromise, high cholesterol, extremity neuropathy, she is legally blind and will need dialysis in the future due to chronic renal failure. She has also been prone to slow-healing infections, bouts of pneumonia and severe flus. Subject D’s diabetes was diagnosed in 1992 as “borderline.” Monitoring and treatment were sporadic and inconsistent; in retrospect, Subject D feels that her diabetes was not taken seriously. She went to the emergency room at the nearest community hospital (20 miles away) for acute situations, such as infection and severe flu. Dental work has been neglected entirely.

Due to an accumulation of diabetic complications, Subject D has had to give up her source of income as a self-employed home health aide, a profession which she loved. She specialized in live-in hospice care. Her yearly income varied greatly, as often she would donate

her services. Her highest weekly wage was \$450; the most she made in one year was \$12,000. “In a sense I was a part of the informal safety net. I was dedicated to help wherever I could,” she observed, “but sometimes I would make too long of a time commitment at very low or no cost to my patient so I would have to play catch up with my own bills.”

Subject D never had health insurance and sought health care only if and when she could afford it. She reports that she was never informed that her family practice clinic had a sliding fee scale for under/uninsured patients and was often asked “can you afford this lab, or this visit today?” She was “caught” by the formal safety net and enrolled in Medicaid in May 1999, only after a prolonged course of recovery from cardiac by-pass surgery performed in December 1998.

She currently receives \$561/month from SSI. Medicaid pays for most of her medication, though she has a co-payment between \$1-10 per medication. Medicaid does not pay for her iron supplements that are necessary for severe anemia. Her pharmacist and diabetes nurse both pressured Medicaid for 5 1/2 months to pay for a \$450 audio glucometer so that she could adequately test her blood sugars. Subject D also has found that Medicaid is very strict about the monthly allowance for equipment for testing and insulin administration (strips, lancets and syringes); when she has expended her supplies allowance before the month is out, she has had to call her diabetes nurse who has been able to find her free supplies. Subject D reported that she is on “about 10 meds four times a day” but was not sure how much out-of-pocket she is spending because her care plan is still being formulated. For example, she was changed from insulin to oral agents after her last hospitalization this spring. Since she is uncertain how her treatment plan will be further adjusted, she does not have a clear idea of her budget.

Subject D clearly articulated several issues raised in this study with regard to limited financial resources, the rural environment, and the provision of diabetes care.

*Lack of Insurance Affects Health Status:* “Not having insurance or enough money to cover medical costs makes you pick and choose; you become your own doctor and you are deciding which illnesses you are going to suffer from this year, and next year, and what you’re not. You try to hope that you’ve picked the right one and that you’ve done the minimal damage

to yourself. The lack of money makes you bypass your doctor and puts it in your hands. It's a frightening experience." For example, Subject D took herself off hormone replacement therapy so that she could afford her hypertension medication and antibiotics for an acute condition. She had been prescribed a variety of oral agents for her diabetes from 1992-1998 (before qualifying for Medicaid), but when the price became too high she ceased her diabetes medication.

*Transportation Is Major Logistical Challenge:* Subject D cannot drive nor does she have family, friends or neighbors to provide this service. She uses the bus from a non-profit social service agency to get to her medical appointments. The service has also agreed to drop her weekly groceries; this seemingly simple task required considerable planning from the diabetes nurse, a volunteer for the home health agency who does the shopping, the bus driver and the social service agency.

*Distance from Services Is Barrier to Access:* It takes Subject D two hours to travel each way to get to appointments with specialists. Though a podiatrist comes to the community hospital on a revolving basis, he is reluctant to take Medicaid patients. When dialysis becomes imperative in her care, the distance will become a graver problem. She has noticed over the years how slowly changes in new technologies and specialists' services come to her area. "The negative side of living in a rural area is the remoteness; when you are not well it is better to be in a place where services are more central. On the other hand, I feel safe here. I know my way around the house, the yard, the town."

*Rural Mores of Self-sufficiency:* Subject D spoke to the potentially dark side of the "character of rural places and tradition" when social networking is not strong within neighborhood or town or when the ethic of self-sufficiency can no longer be sustained because of disease. "It is a town without pity. It is stark, is what it is. You better have health, enough money to take care of yourself, and most of all, you better be self sufficient. There is a silent code that everybody lives by 'don't ask for anything, expect nothing'."

*Mental Health Implications of Diabetes* "When everything started to pile up, all these serious illnesses, I needed some sort of help because I was so overwhelmed and just unable to



handle it all; I've been bordering on depression.” Furthermore, Subject D described feeling isolated and imprisoned as her physical condition has declined. She worries whether she will be able to remain in her own home. “Who will do the snow plowing so the ambulance can get in if I need it?”

*Sporadic Care of Diabetes as Precursor to Complications:* Subject D's “borderline” diabetes was not treated with a comprehensive care plan; she did not have consistent glycemic control, diabetes education and regular testing and follow-up; her diabetic complications “came on all at once. I never expected that I would be in this situation.” Within the last year, even after it had become apparent how severely diabetes had affected her, she was put on a strict high protein, low carbohydrate diet. The physician insisted that weight loss was the top priority and only upon repeated phone calls from the diabetes nurse did he order a microalbumin urine test which revealed Subject D's renal failure.

*Team Approach Geared Toward Individual Needs:* Subject D now has two nurses from a home health agency, one of whom is a diabetes specialist and who addresses her diabetes education, a representative from Maine Center for the Blind, three CNA's to ensure that dietary and monitoring requirements are met, a “mobility trainer,” and a social worker, all of whom come to her home. This cadre of providers is in addition to a new primary care physician, an ophthalmologist, a cardiologist, and a nephrologist.

*Strength of the Informal Safety Net Depends Upon Provider:* Before Subject D became enrolled in Medicaid, very few resources were offered to her; most notably the drug assistance programs were minimally and inefficiently accessed. When she became assigned to a visiting nurse with a diabetes specialty, her diabetic needs were specifically addressed and Subject D was afforded access to goods and services provided by the formal and the informal safety net.

**Table 4. Summary of Case Studies**

	Insurance	Annual Income	Annual out-of-pocket medical expenses
Subject A	Uninsured	22,600*	1300
Subject B	Medicare	29,900*	5100
Subject C	Anthem/BCBS	12,500	6970
Subject D	Medicaid	6,730	1800

\* Includes spouses income

### ***The State of the Informal Safety Net in Northern New England***

Understanding how the informal safety net works—how it provides or helps to provide the complex array of services required by those with diabetes—requires an understanding of the various services that are available, but also requires an understanding of the attitudes and perspectives of providers, many of whom deliver free or reduced cost care. Our interviews with providers and administrators in Maine, New Hampshire and Vermont addressed these two key elements of the informal safety net.

*Medical Providers:* As suggested by Subject D in the previous section, having a provider who is not only committed to offering free or reduced cost care, but who is also connected to or willing to reach out to other providers of needed services is crucial. A nurse who has lived all her life and practiced nursing for 20 years in the same area, reinforced the positive aspect of small town collegiality. “It’s a small community. When I call and say my name, they know who I am and what I do. I’m not just a face and name in the crowd. There is a lot of credibility in this that really helps when I call the docs, or particularly the nurses with whom I have a tremendous networking, and say ‘I need to get so & so in,’ or ‘I need meds or strips, what can you do.’”

A physician interviewed, who practices in a larger community provided an added insight:

The informal safety net has to be built on collegiality. Unfortunately medicine has changed from when I started practice and everything was collegial. We knew everybody in the community. We’d call another practitioner and say ‘I’d like you to see Mr. Jones here who has

diabetes and a sore on his foot; he ought to see somebody but he doesn't have insurance so let's share the load.' It's kind of fallen by the wayside. Certain practices stand out who will do this, but newer docs, driven by managed care, don't have the same connectedness to medicine as a profession. It's a business, just business.

In a locale where these elements of coordination and cooperation are missing, the informal safety net is fragmented. An RN/RD (registered dietitian) who conducts diabetes education classes in a community hospital acknowledged a disconnection from other providers and community resources in her area, and, though she was able to procure free testing supplies for her clients, she did not have a network of other providers to which she could refer patients who were in financial straits. "That (the network) is something we really haven't tapped into. It's probably something that needs to be done and investigated more, but at this point I am spread so thin."

A nurse practitioner commented on the effort and dedication required in pulling the threads of the informal safety net together for patients. "It takes a lot of effort to do what we do. Not every practice down the road will take that effort." A physician interviewed stressed that commitment over time has to be made; it's not a "one night stand" to work in a free clinic such as his. A case manager at a free clinic applauded

...the wonderful community of health providers who are aligned with our mission of caring for uninsured people. Even though there is a level of burnout and volunteering evening hours after a long day at work is often difficult, the work is very satisfying and different from the office practice which is boom, boom busy, five patients an hour, paperwork, insurance, maybe not being able to practice the way they'd like to practice sometimes. I think the clinic offers them a respite from that.

Several providers told stories of colleagues unwilling to accept patients without insurance for financial reasons and because of a value-laden perception of people unable to pay their bills. "I have a friend who won't volunteer for the clinic claiming that he will see "them" in his office, but then I overhear him talk about the "ones" who can't pay his bill but spend their money on a new truck or three packs of cigarettes a day. It's a definite attitude." Overcoming bias toward people unable to pay for medical care becomes a necessary component in soliciting help in the informal safety net. The converse attitude toward potential clients was expressed by a nurse/case

manager of a free clinic:

It's a fine line trying to find out what people can afford and not make them feel inadequate. I want to preserve people's dignity. My philosophy is that many of them have suffered a lot of indignity in their lives; being poor is hard. I want to give them dignity. I believe in people and I want them to feel good about themselves, and my sense is that they can feel good about themselves coming here; they don't have to feel it's a problem if they can't pay.

*Access Programs:* The process of *formalizing the informal safety net* is attracting increased attention in New England. One Project Director of a newly created access program noted, "We know we will be able to meet only a small percentage of this huge need and that our success will depend on bringing others into the effort. This isn't going to solve the problem, but it will provide a model for how it can be solved" (MaineHealth Family, Vol 4. No.2).<sup>2</sup>

*Free Clinics:* The level of service varies from clinic to clinic in New England: primary and preventive care, referrals to specialists, prescriptions assistance (local pharmacies, doctors' samples, pharmaceutical company programs), and complimentary health care (e.g., weight reduction, chiropractic). We contacted one clinic in Vermont that also offers a dental clinic; access to dental care for uninsured and even Medicaid recipients was identified as a problem in all three states making this clinic unusual.

Most clinics have a core of paid staff members as well as volunteers. Paid case managers and clinic coordinators play a significant role in the overall success of free clinics as do volunteers. Often an RN or Nurse practitioner is both case manager and clinic director. Not only do these individuals solicit and schedule volunteer providers, enroll patients, screen patients for available state programs, but they coordinate patient care and follow-up thereby assuring continuity of care, a concern that many physicians have with regard to free clinic care. This case management function is particularly vital in providing care for chronic illness such as diabetes.

As case manager it is my responsibility to get the client to carry through with his/her care plan that has been designed by the doctor. I get the referrals going, call the patients afterwards, make sure they understand everything. Since our physicians are a rotating slate of volunteers,

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<sup>2</sup> Examples of access programs include HealthLink/Laconia, NH; Community Health Connections, So. York County, ME; MATCH, August/Waterville, ME; MaineHealth Access, Cumberland, Kennebec, Lincoln Counties, ME

we don't go by anyone's particular protocol as far as how a patient is seen, but if I take the chart and see that the patient came in with polyuria, was identified as having high blood sugar in the lab work that was ordered by last week's doctor, it is my job to brief this week's doctor and to understand what the next step in treatment is. That way I am involved in every step of the way and I am really the constant person that the patient sees or talks to. With diabetes all kinds of things are needed--labs, dietitian, eye doctor, education-- it is my job to be on top of all of that. It is an illness that requires intense amounts of time teaching patients to care for themselves, to be responsible in terms of diet, exercise, lifestyle changes, medications, following up.

Free clinics were visited in both Vermont and Maine. Vermont displays a further formalizing of the informal safety net in the Vermont Coalition of Clinics for the Uninsured (VCCU) which is a consortium of nine clinics with its own 501(c)(3) status. Each clinic operates independently but coordinates within the Coalition.

Without the availability of free clinics and access programs, patients report that they forgo or delay care; others use the emergency room (Nelson 1999). In the case of diabetes, both providers and subjects in this study reported that the emergency room is not used by people with diabetes for management issues but rather for acute episodes of conditions that are complications of diabetes, such as severe infections, pneumonia, heart attacks.<sup>3</sup>

*Support Groups:* One support group visited in this study has been meeting once a month for several years with a fairly steady attendance of a core group of primarily women above fifty. It has been led by the same CDE who donates her time and devotes the sessions to all aspects of diabetes care from stress management to foot care. She noted that the group is a "vital part of the ongoing education component of her clients' self-management."

*Screenings:* One New Hampshire hospital conducts a yearly free diabetes screening called the "Diabetes Drive-Thru"; individuals drive through the hospital parking lot, fill out a simple information form on demographics and risk factors, have their blood sugars checked, and receive educational material on diabetes. The hospital administrator interviewed reported that this program, a part of their community outreach and prevention strategy, has grown in

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<sup>3</sup> In a study which looked at use of the ER by people with diabetes as a chronic disease in a rural setting it was found that people with diabetes used the ER less than 2 other groups in the study (COPD and random) and that use of the ER was not for diabetes management. "Analyses of charges showed that ER use by people with diabetes is more expensive than that for other populations. These excess costs are accounted for my complications of diabetes rather than for diabetes care." (Calvert, 2000)

popularity each year. They also conduct free diabetes screenings in supermarkets and schools.

*Pharmaceutical Companies:* A drug company representative interviewed for this study perceived a “huge gap” in the delivery system of health care products; it “is not even close to meeting the needs of people with diabetes.” She reported that it is not unusual for physicians and educators to call her (and reps from other companies) requesting products beyond those that are left at offices. Educators and nurses interviewed for this study report that they value the working relationship they have with many of the reps who they can call if there is an immediate patient need.

Participation in these programs depends heavily on physicians’ knowledge of and organizational capability to administer the paperwork for patients. Use of the patient assistance programs varies widely from office to office, clinic to clinic. One of the most successful examples of utilization of these programs was a Federally Qualified Health Center (FQHC) in Vermont where a full time intern maintains a tracking system matching patients’ pharmaceutical needs and pharmaceutical companies’ requirements in order to keep the dispensing of drugs and equipment consistent and flowing. The social worker at this clinic estimated that her system has brought in \$600,000 worth of drugs in the last five years for a patient base of 10,000. This informant was unable to extract diabetes related figures . At a family practice in New Hampshire, a key informant stated that since affordability of medication was of such concern to her patient population, utilization of the indigent drug programs had become a top priority in the practice, and a nurse was now spending a majority of her work week developing an effective tracking and dispensing system. The effectiveness of these programs is heavily dependent on physicians’ offices’ efficiency in administering them.

*Community Organizations:* The Kiwanis sponsorship of a free clinic was notable

in this study. This local chapter operates the clinic under its non-profit status, By-Laws and Board of Directors, raises approximately \$10,000 yearly for operating costs, solicits and schedules the volunteer providers, and handles administrative matters. The Lions Club was also mentioned several times in this study as a resource for eye care, either with direct payment for eye exams or free glasses.

A unique model of a community volunteer health association was seen in a rural town in this study and is worthy of mention. The group was started approximately 40 years ago by the town nurse, a now-defunct town-paid position. The remaining members of the group have always been volunteers. The Association has 501 (c) (3) status and receives private donations to cover costs.

The Association services 200-300 people per year, both vacationers and locals in the area. They do not advertise; they receive referrals by word-of-mouth and from local providers including but not limited to pharmacies, the school nurse, Town Hall, the VNA. There is no official record keeping, however association members have developed detailed knowledge of many local residents and their families over time. The group dispenses Christmas baskets of food & clothing for needy families, organizes and/or sponsors HepB vaccine and flu shot clinics, and recycles medical durable equipment (stored in the informant's garage and at Town Hall).

The group has built a relationship over the years with local physicians and dentists who are open to treating patients with no or limited ability to pay, and vendors who will donate goods (e.g., pharmacies give personal care items and medications). The informant related an example of how diabetes goods "flow": a woman with insulin-dependent diabetes gave the group a considerable number of new, unused syringes. The woman's insurance policy would only cover one type of syringe and because this syringe was not appropriate for her, she was willing to pass

them on to somebody else who could not afford syringes at all and used the health association as a conduit for her contribution. The informant also has a good relationship with the VNA with whom she exchanges supplies and equipment. The group maintains a small scholarship fund to send children with diabetes to summer camp, and to help with their medication and equipment.

## **V. DISCUSSION AND POLICY IMPLICATIONS**

Our analysis of national data indicates that residents of small rural communities are at greater risk for diabetes, and, due to low incomes and lack of health insurance, have a greater need of the safety net than urban residents. Although rural diabetics are no more likely to be uninsured than their urban counterparts, they are more likely to delay care due to cost, suggesting that rural insurance policies may offer poorer coverage of needed services, or that the urban safety net does a better job of providing needed services that are not covered by insurance.

Both national and regional findings indicate that inability to pay is a significant barrier to optimal management of diabetes for rural residents. Numerous providers and recipients of health care interviewed in this study reported that: 1) there are physicians unwilling to treat without assurance of reimbursement; 2) there are insurers not willing to pay for all goods/services required in the care of diabetes; 3) patients are not seeking care, or are receiving sub-optimal care, due to a combination of factors related to their ability to pay, including having to make choices among treatment modalities or between medical needs and other living expenses, cutting costs by splitting pills (i.e., one 500 mg pill costs less than two 250 mg of same), reusing syringes and lancets, or spreading out their testing schedule, (i.e., instead of testing 2-3 times a day, testing one day in the morning, the next day at lunch, the third day at supper); and 4) being well insured, either with a private or governmental policy, is not a guarantee against economic and psychological hardship caused by medical bills. In addition, the loss of self-respect arising from inability to pay, combined with the stress of struggling to obtain basic care, may lead to additional medical or psychological problems.

Within the parameters of current standards of clinical practice, diabetes demands a



network of medical providers using a “team approach”, ongoing training and self-management education, a multitude of medications, durable equipment, labs, and regular monitoring and follow-up. Because of its complex and chronic course, diabetes amongst the rural un/under-insured of northern New England places extraordinary strain on the informal safety net, and the increasing prevalence of this disease in these areas magnifies this strain. Such coordination is difficult to achieve in rural areas due to the distribution of providers and services. It is also difficult to achieve when some of these services are provided by a patchwork of informal and sporadic sources of free care.

Despite the inadequacy of insurance, the difficulty of coordinating care, and the difficult choices faced by many rural residents, the informal safety net in some rural northern New England communities is rising to the challenge, providing needed services, coordinating care, and improving the lives of uninsured and underinsured people with diabetes. While much of this effort is observed at the grass roots level, relying on lay volunteers as well as the generosity of providers, the safety net programs offered by large national pharmaceutical companies are making a major difference in the lives of those patients who are able to qualify for them. For the most part, however, the existence, strength and duration of the informal safety net depends upon the commitment of individuals to serve those without the ability to pay. The safety net is based on philosophical, ethical, and moral commitment, and requires sacrifice of time, energy, and remuneration. It also requires a shared compassion, a concern for public health, and a sense of collegiality among providers at various levels of the delivery system, as well as logistical networking. The informal safety net in rural areas is stretched because distance makes personal networking more difficult. The remoteness that is felt by patients can also be felt by the provider community. Furthermore, the informal safety net is not inherently self-replicating; good will alone does not ensure sustainability.

Use of the informal safety net by patients is influenced by the degree to which it is made accessible by the provider world. Without knowledge of free screenings, support groups, and pharmaceutical company programs, patients often are isolated in a world of limited options.

## ***Policy Strategies***

*Insurance coverage must be consistent with the standards of care.* Since a major factor contributing to sub-optimal management of diabetes is the failure of insurers to cover all recommended continuing care, the strain on the safety net could be lessened by insisting that insurers including Medicare and Medicaid, modify definitional loopholes and utilization limits in order to follow the spirit of state mandates in payment for supplies, equipment, education, and prescription drugs.

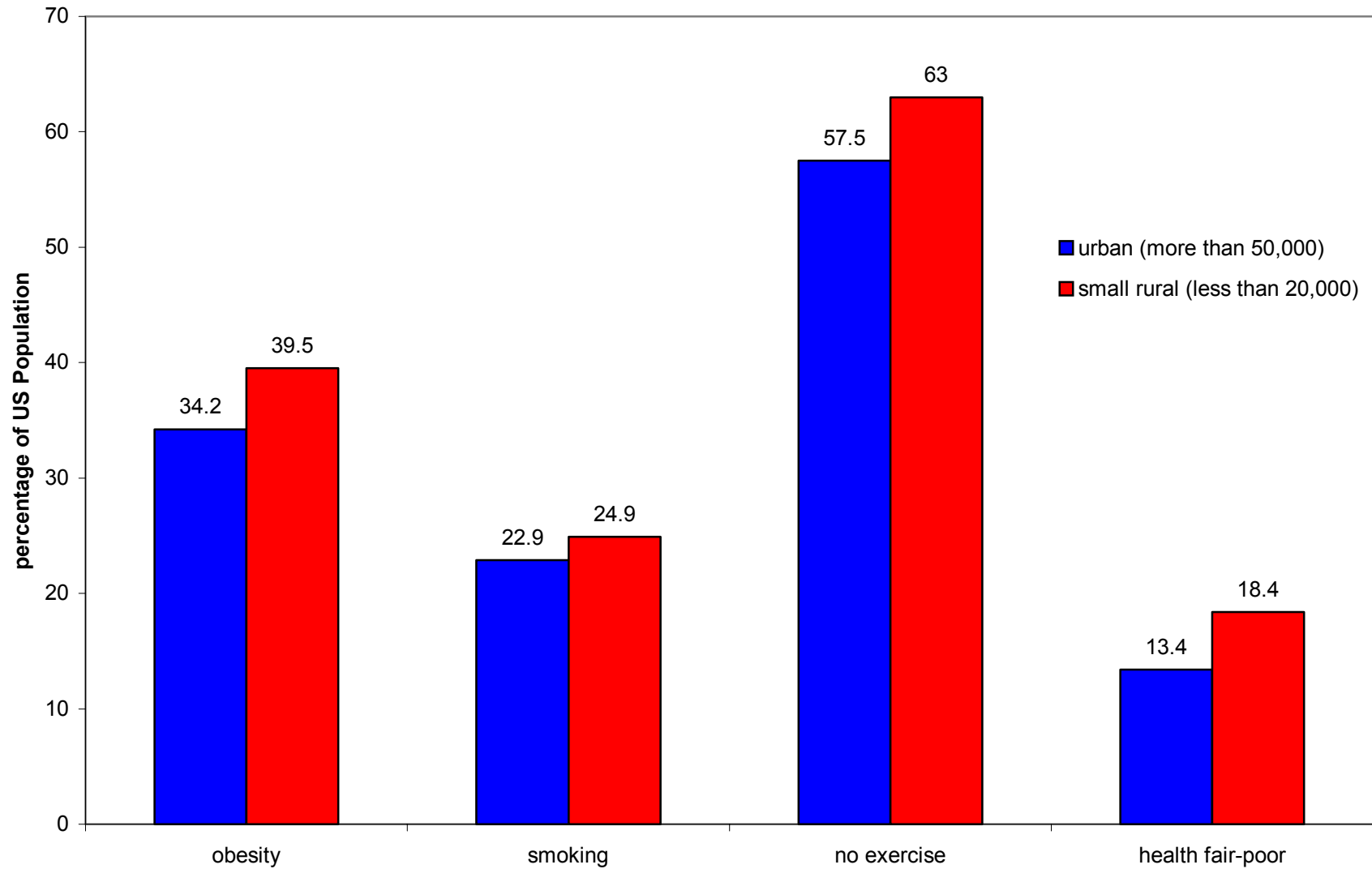
*Facilitate team management and care coordination.* To intensify the commitment to a team concept in diabetes care, partnerships between local public health workers, diabetes educators, and safety net providers must be encouraged. This means encouraging provider participation in community outreach and community education initiatives. Such partnerships may also help safety net providers to share the burden of free care more equitably, and may serve to keep providers informed of clinical standards of diabetes care, mitigating complications, and thereby reducing the demand on the safety net. To facilitate team management, federal and state grant programs such as the community access program, rural hospital flexibility grants, and CDC grants targeted to diabetes, should require provider-to-provider networking and other team-building strategies as a condition for receiving funds. The CDC should also consider offering grants to state health departments to establish rural diabetes resource centers to centralize services, to equitably distribute specialists and technology, and to disseminate information/education resources to clinical practices and patients alike.

*Formalize the informal safety net.* Community-based mechanisms to formalize the delivery and coordination of free care and services are needed, with stable funding that is not totally dependent on private sector or foundation grants. Access programs are a step in the

development of such mechanisms, but their dependence on grants raises questions about their sustainability. Formal safety net programs such as migrant and community health centers should be expanded, as planned by the current administration. In addition, states should encourage and facilitate the development of semi-formal safety net mechanisms like the Vermont Coalition of Clinics for the Uninsured.

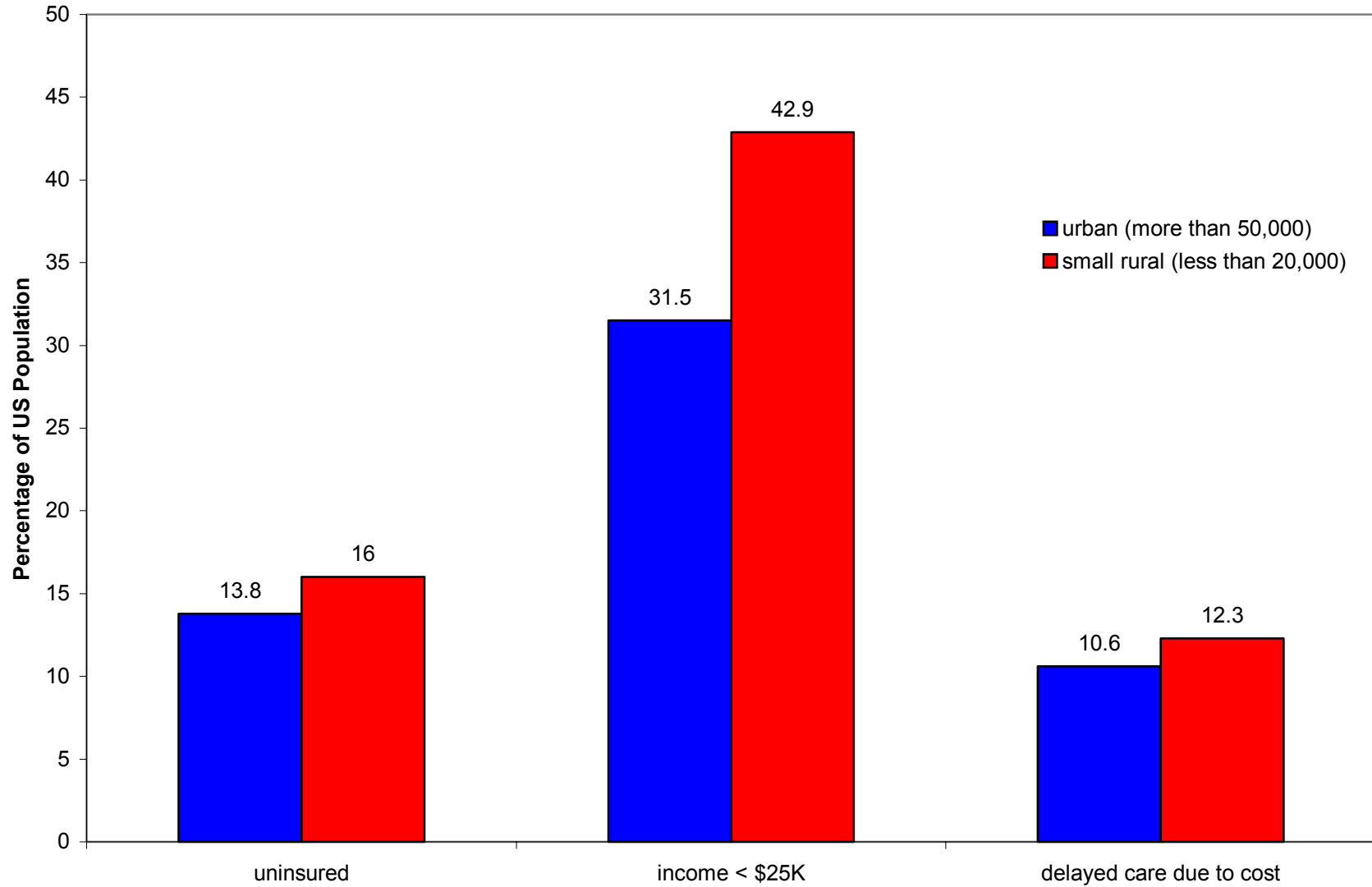
*Further research is needed to better understand why rural residents are at greater risk for diabetes.* Our finding, corroborated by other studies, that rural residents get less exercise, are more likely to smoke, and are more likely to be obese than their urban counterparts, is disturbing. One might hypothesize that the lack of sidewalks, bike paths and health clubs or the lack of dietary variety are contributing factors. Or one might argue that the lack of such amenities is a choice made in the context of a rural culture. At the beginning of the twentieth century the rural life was thought to be the healthy life. It is unsettling to think that, over the course of the past 100 years, an unhealthy rural culture has evolved to replace the vigorous, healthy lifestyle idealized by Theodore Roosevelt. A third hypothesis, supported by recent research on the social determinants of health (Marmot and Wilkinson 1999, Evans, Barer and Marmor 1994) would suggest that the lower socio-economic status of rural populations is a significant determinant of health behaviors. These are intriguing and researchable questions.

**Figure 1. Risk Factors for Diabetes: US Population**



Source: Centers for Disease Control, Behavioral Risk Factor Surveillance System 1996 – 1997.

**Figure 2. Characteristics of Rural and Urban Population Indicating Need for Safety Net**



Source: Centers for Disease Control, Behavioral Risk Factor Surveillance System 1996 – 1997.

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## Appendix A

### ADA STANDARDS OF CARE

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#### Screening for all at-risk individuals

- ☑ Fasting plasma glucose (FPG) and/or Oral glucose tolerance test (OGTT)

#### Initial Visit

- ☑ Thorough medical history
- ☑ Thorough physical exam
- ☑ Lab eval: fasting plasma glucose, GHb, fasting lipid profile, serum creatinine, urinalysis (glucose, ketones, protein sediment, microalbumuria), urine culture (if indicated), thyroid-stimulating hormone (TSH)[Type I], EKG (adults)
- ☑ Design of individualized management plan: goal-setting, medications, nutrition, lifestyle changes, education for patient and family, monitoring instructions, dental hygiene, vaccinations, consultations for specialized services as indicated

#### Continuing Care

- |   |         |
|---|---------|
| ☑ Primary Care exams (Weight, blood pressure, foot exam, re-assess tx plan) | 2-4x/yr |
| ☑ HbA1c (blood glucose)   | 2-4x/yr |
| ☑ Lipid profile   | 1x/yr   |
| ☑ Urine screen (renal function)   | 1x/yr   |
| ☑ Ophthalmologist (retinal exam)  | 1x/yr   |
| ☑ Podiatrist (comprehensive foot)   | 1x/yr   |
| ☑ Immunization (influenza & pneumonia)                                      | 1x/yr   |
| ☑ Self-monitored blood glucose testing (SMBG)                               | Daily   |
| ☑ Self-Management Education   | Ongoing |
| ☑ Medical Nutrition therapy   | Ongoing |
| ☑ Obesity treatment and management  | Ongoing |
| ☑ Exercise programs   | Ongoing |
| ☑ Tobacco counseling, cessation programs                                    | Ongoing |
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## Appendix B Estimate of Potential Costs of Diabetes Care

(Estimates, based on case studies and interviews. Where no cost is indicated, items are included as examples of additional costs that might be incurred.)

### Testing:

Glucometer	\$30-70
often find deals with rebates-companies give away or make deals to get strip business-special sales	\$5-20
Roche makes Acu-Check for \$19, #3 selling gluc nationwide	
Test Strips depends # tests/day; avg \$2-3/dy	\$70/100
Lancets - depends # tests/day-included in \$2-3/dy	\$10/100
Lancet device	\$28
Control Solution	

### Insulin administration:

Insulin (100 units = 1ml)	avg \$24/vial
Humalog 10ml vial \$30.78; 1.5ml cartridge,cnt 5 \$39.02	
Humulin 70/30 10ml vial \$22 (Internet pharm)	
Humulin L 10ml vial \$22 (Internet pharm)	
Humulin N 10ml vial \$22 (RiteAid \$25.98 10ml:\$20/pen=3ml-needs script)	
Humulin R 10ml vial \$22 (Internet pharm)	
Humulin U 10 ml vial \$22 (Internet pharm)	
Syringes	\$27.98/100
Syringe alternatives	
Pen needles w/ cartridges	\$35-40
Insulin pumps(continuous delivery)	\$5000
Auto-injectors(loaded syringes frocing insuling through skin-not puncture)	
Infusers(creates portals into which insulin injected)	

### Oral Diabetes Medications (1-3x/dy)

Amaryl	1x/dy	4mg	\$33.69/30
Actos	1x/dy	30mg	\$163.98/30
Avandia	1-2x/dy	4mg	\$174.69/60
		8mg	\$315.69/60
Diabinese	1x/dy	250mg	\$35.98/30
Generic Chlorpropamide		250mg	\$24.69/30
Diabeta or Micronase	1-2x/dy	5mg	\$72.69/60
Generic Glyburide		5mg	\$31.98/60
Diabinese	1x/dy		
Dymelor	1-2x/dy		
Glucophage	2-3x/dy	500mg	\$80.69/90
Glucotrol	1-2x/dy	10mg	\$59.98/60
Generic Glipizide		10mg	\$37.98/60
Glucotrol-XL	1x/dy	10mg	\$31.98/30
Glynase, Pres tab	1x/dy	3mg	\$33.69/30
Generic Glyburide Micro		3mg	\$24.69/30
Glyset	3x/dy		
Orinase	2-3x/dy	500mg	\$52.69/90
Generic Tolbutamide		500mg	\$29.98/90
Prandin	3x/dy	1mg	\$86.98/90
Precose	3x/dy	50mg	\$60.69/90
Tolinase	1-2x/dy	250mg	\$65.98/60
Generic Tolazamide		250mg	\$20.98/60

Exercise Program @ YMCA membership \$336/yr; Yk Hosp Cardiac Risk Reduction \$1511.15 for 8wk program including \$597 treadmill

Wgt Control Program Weight Watchers \$500-600/yr

Smoking Cessation Program \$80/8wk (York Hrt Ctr)

Diabetes Education York Hosp \$400 , Exeter \$350 ADEF \$350, Goodall Hosp \$105

Nutrition Counseling - When not included in diabetes education programs, \$60 initial visit, 20-40 follow-up Office Visits: Exams & Evals Variations depending on age of patient, initial or established, kinds of procedures and tests done.

	Consult	Initial	Estab Yrly	Follow-up
Internist/Family phys		130-175	120-145	20-80
Podiatrist		70-90		40-80
Ophthalmologist		115		70
Endocrinologist	145-255	115-150		60-100
Cardiologist	110-264	70-185		55-100
Nephrologist	360/mon includes rounds, office visits during dialysis			
	Dialysis tx (13-14/mon): commercial ins chg 540-575/tx: medicid/medicare 117/tx; ancillary costs including meds/tx 140			
Neurologist				85
Orthoped				
Mental Hlth				
Social Work				
Dental				
Wound center	130	70-100	40-60	

Labs (range given of outpt-inpt)

HgA1C 2x/yr or qrtly	28-52
Urinalysis (glucose, ketones, protein, sediment) 1x/yr	13-40
Serum creatinine	21-36
Fasting plasma glucose	13-16
Microalbuminuria	20-60
Fasting lipid profile (tot cholesterol, LDL, HDL, triglycerides) 1x/yr, or every 2 if in control	39-57
Thyroid	44
Hepatic function panel	26
EKG	65

Miscellaneous personal products: Though each item may be under \$10, quantity varies with each individual.

- Alcohol, antiseptics, topical antibiotics
- Athlete's foot & antifungals
- Carrying case
- Diarrhea treatments
- Diabetic skin & foot care (creams, powders, lotions, socks)
- Medical ID tags
- Oral care & lip balms
- Personal lubricants
- Sugar free medications (cough, cold & flu..)
- Vaginal (itch relief/moisturizers)
- Yeast infection treatments

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