

New York State  
Strategic Plan  
for the  
Prevention and Control  
of Diabetes

# NEW YORK STATE PLAN FOR THE PREVENTION AND CONTROL OF DIABETES

## DIABETES OVERVIEW

### What Is Diabetes?

Diabetes is a major chronic disease in the United States. Over 18 million Americans have diabetes, and 1.3 million new cases are diagnosed each year. New estimates indicate that up to another 37 million Americans have “pre-diabetes,” a condition in which blood glucose levels are higher than normal but not yet in the diagnostic range for diabetes, known as Impaired Glucose Tolerance (IGT) or Impaired Fasting Glucose (IFG). Most people with this condition go on to develop type 2 diabetes within 10 years. There is an urgent need to address this insidious disease. Diabetes is characterized by high blood glucose levels (hyperglycemia) resulting from defects in insulin secretion, insulin action, or both. The two most common types of diabetes are type 1, accounting for about 5-10% of all diabetes, and type 2, accounting for about 90-95% of all diabetes. Type 1 is an autoimmune disease characterized by destruction of the beta cells of the pancreas, usually leading to absolute insulin deficiency. Type 2 is characterized by insulin resistance and relative insulin deficiency. Type 1 diabetes develops most often in children and young adults, though it can appear at any age. Type 2 diabetes usually develops in adults over the age of 45, but has become increasingly common among obese individuals of all ages, including children and adolescents. Gestational diabetes occurs in 2-5% of all pregnancies. It is often a precursor for developing type 2 diabetes later in life.

If not controlled, diabetes can lead to serious chronic complications in the eyes (retinopathy), kidneys (nephropathy), peripheral nerve system (neuropathy), and arteries (atherosclerosis). Diabetes can affect nearly every organ system of the body and is a leading cause of blindness, end-stage renal disease, lower extremity amputation, cardiovascular disease, cerebrovascular disease, and peripheral vascular disease. Uncontrolled diabetes can also cause acute complications such as hyperglycemia, diabetic ketoacidosis and lactic acidosis. Women with pre-existing diabetes who become pregnant are at risk for delivering babies with preventable congenital malformations and perinatal mortality.

Diabetes can be controlled effectively by a combination of medical and self care. For people with type 1 diabetes, daily insulin administration is necessary. People with type 2 diabetes usually require a combination of physical activity and proper nutrition, often combined with oral medication and in some cases insulin, for good control. All people with diabetes require self-management, including monitoring of blood glucose levels, managing diet and exercise, and checking for signs of complications. Diabetes is a chronic condition that affects all major organs in a progressive way. Currently there is no cure. People with diabetes are challenged to manage their disease 24 hours-a-day throughout their lifetime. Periodic examinations by health care professionals to monitor hemoglobin A1c levels, blood pressure, blood cholesterol, feet, eyes, oral health, kidney and liver function are also necessary. Due to the physical, hormonal and emotional growth that occurs during childhood, children with diabetes require additional considerations for the determination of appropriate medical care and self care. Often the type of medical care and self-care is dependent upon the developmental stage and maturity of the child, which adds to the complexity of this disease.

## Who is at Risk for Diabetes?

Understanding risks for diabetes is an important step toward preventing onset of the disease and identifying populations at risk. Major risk factors for type 2 diabetes are increasing age and certain hereditary and behavioral traits. Heredity risks include having a first-degree relative with diabetes and being Native-American, African-American, or Hispanic. Being overweight, defined as having a body mass index (BMI) of 25 and over, or obese (BMI of 30 and over) and being physically inactive are behavioral risks. Women who have delivered a baby weighing 9 pounds or more or who are diagnosed with gestational diabetes are also at higher risk. Possible risk factors for type 1 diabetes include consumption of cow's milk during infancy and certain viral infections. Recent research has identified a number of genes that are linked to type 1 diabetes.

Modification of a behavioral risk has proven to be effective for preventing type 2 diabetes in adults. Increasing physical activity, reducing intake of food high in calories and fat, increasing consumption of dietary fiber, and smoking cessation are positive changes for preventing diabetes. Controlling blood pressure, cholesterol levels, and weight are also important for reducing the risk for diabetes. Promotion of healthy lifestyles should also target children and adolescents, as more and more children and adolescents are becoming overweight, increasing their risk for early onset of type 2 diabetes.



## Current Diabetes Issues

The occurrence of diabetes, especially type 2 diabetes, is increasing in the United States. The prevalence of self-reported diabetes among adults increased from 4.9% in 1990 to 7.3% in 2000, a 49% increase. This trend has a strong association with the epidemic of obesity. According to the 1999-2000 National Health and Nutrition Examination Study (NHANES), almost one third of U.S. adults are obese. From the same data, 16% of children aged 12 to 19 and 15% of children aged 6 to 11 are overweight (i.e., have a BMI at or above the 95th percentile of the sex-specific age growth charts). The prevalence of both obesity and diabetes are elevated in ethnic minority groups including African-Americans, Hispanics, Native Americans and certain groups of Asian-American and Pacific Islanders. The Pima Indians in Arizona have the highest prevalence of diabetes and obesity. Diabetes prevalence is also high among those with less than a high school education.

Despite advances in knowledge of diabetes care and control, diabetes is still a leading contributor for impaired quality of life, disability and mortality in the United States. Diabetes is now the sixth leading cause of death in the United States, primarily from diabetes-associated cardiovascular disease.

Diabetes is the leading cause of non-traumatic lower extremity amputations and end-stage renal disease. It is also the leading cause of blindness among adults aged 20 to 74. People with diabetes are at increased risk for infectious diseases and depression.

Diabetes is a costly disease. Estimates of the total costs attributable to diabetes are approximately \$132 billion per year in the United States. Hospitalizations for diabetes-related cardiovascular disease account for the largest component of the total cost of diabetes care. People with diabetes use emergency rooms and outpatient facilities more often than people without diabetes, often require a high level of trained homecare services, and are found in increasingly large numbers in long-term care facilities and psychiatric facilities.

The burden of diabetes – morbidity, disability, mortality, and costs – is disproportionately large in certain segments of U.S. population. Disadvantaged ethnic and racial minorities in inner cities, Native American reservations, and rural migrant camps, for example, suffer from higher prevalence of diabetes, its complications, and resulting premature deaths. Disparities in diabetes burden have roots in wider public health issues including health care coverage and access, quality of medical care and self-care, and language and cultural barriers in health communication. Social issues associated with low socio-economic status and immigration also play a role in the disparities of diabetes burden.

## Diabetes Trends in New York State

Based on a study of Behavioral Risk Factor Surveillance System (BRFSS) data, 6.7% of all adults (approximately 960,000) in New York State are estimated to have diagnosed diabetes. An estimated additional 450,000 adults have diabetes but remain undiagnosed. Because of a relatively long asymptomatic period, people with type 2 diabetes often do not realize they have the disease until a complication develops, at which point there is less opportunity to mitigate the consequences of the disease with lifestyle interventions.



The current prevalence of diabetes represents a 50% increase since 1993, when only 4.4% of adults in New York State had diagnosed diabetes. While some of this increase may be due to the fact that people are being diagnosed earlier, an increase in obesity stemming from changes in people's lifestyle is likely to account for much of this trend. In New York State, the percentage of obese adults increased from 14.8% to 20.3%, a 37% increase during the same period.

While New York State's diabetes prevalence equals the national median value (ie. when states are ordered by prevalence from the lowest to the highest, equal numbers of states are above and below New York State), certain sub-populations in the state have significantly higher prevalence of diabetes. Surveys conducted by the New York State Department of Health indicate that African-Americans, Puerto Ricans, and Russian-speaking immigrants have a prevalence of diabetes almost twice that of non-Hispanic whites.

Other indicators of diabetes, including diabetes-related hospitalizations, mortality, and incidence of major complications, saw only small changes over the last several years. Because of the slow progression of diabetes, it will take time to see the impact of interventions that affect those measures. The following summarizes major indicators of diabetes in New York State:

- In 2000, there were over 354,000 diabetes-related hospital discharges. The rate of hospitalization has decreased from 442.6 per 1,000 people with diabetes in 1997 to 390.3 per 1,000 people with diabetes in 2000. (New York State hospital discharge data 2000)
- In 2000, the average length of a diabetes-related hospital stay was 7.9 days, with the average charge of \$17,800 per stay. There is a slow but steady trend of declining length of hospital stay and increasing charge per stay. In 1997, the average hospital stay was 8.9 days and the average charge was \$15,400. (New York State hospital discharge data 2000)
- In 2000, there were 3,980 death certificates filed with diabetes listed as an underlying cause, corresponding to an age/sex adjusted death rate of 20.2 deaths per 100,000 people. The mortality rate slightly increased from previous years. In 1997, diabetes-related age/sex adjusted mortality rate was 18.9 deaths per 100,000 people. This increase may represent a greater awareness of the relationship between diabetes and its devastating complications. (New York State Vital Statistics 2000)
- In 2000, there were 6,414 lower extremity amputations as a complication of diabetes. The rate of amputation was 7.1 per 1,000 people with diabetes, indicating a slight increase from 6.9 per 1,000 people with diabetes in 1997. (New York State hospital discharge data 2000)
- In 1998, there were 2,497 new cases of end stage renal disease among people with diabetes at the rate of 3.2 per 1,000 people with diabetes. This rate is a slight decrease from the previous year's rate of 3.4 per 1,000 people with diabetes. (End Stage Renal Disease Network of New York 1998)
- In 2000, there were 9,543 births to women who had pre-existing diabetes or gestational diabetes. The rate of births to women with diabetes was 3.7%, representing a slight increase since 1997. (New York State Vital Statistics 2000)

No comparable data regarding children and adolescents with diabetes are currently available in New York State.

## Diabetes Care in New York State

Monitoring and improving diabetes care in all types of clinical settings is crucial for improving the conditions of people with diabetes and reducing long-term diabetes-related health care costs. There are several sets of measures currently used to assess quality of care. The American Diabetes Association (ADA)'s Standards of Medical Care for Patients with Diabetes Mellitus are clinical guidelines that are often adopted as the "best practice" model for diabetes care specialists. The Healthy People 2010's diabetes care objectives are used as goals for public health practitioners whose mission is reducing the burden and closing racial and ethnic disparities in diabetes complications and mortality. For managed care organizations, the National Committee for Quality Assurance (NCQA)'s Health Plan Employer Data and Information Set (HEDIS) Comprehensive Diabetes Care measures serve as performance indicators of diabetes care. Evolved from the HEDIS are the Diabetes Quality Improvement Project (DQIP) measures, created jointly by the Centers for Medicare and Medicaid Services (CMS), NCQA, and ADA. The DQIP measures are designed to provide diabetes-specific accountability measures for all types of practices. Finally, Coordinated Performance Measurement for the Management of Adult Diabetes serves as performance measures as well as practice guidelines for clinicians. This set of measures was developed by collaboration among the American Medical Association (AMA), the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and the NCQA.

New York State collects key diabetes clinical indicators among managed care organizations through Quality Assurance Reporting Requirements (QARR). QARR adopts HEDIS measures and some state-specific performance measures. In addition, self-reported diabetes clinical care and self-care practices are assessed by the BRFSS diabetes modules. The following summarizes recent statistics regarding diabetes care in New York State.

- In 2000, 79% of commercial managed care enrollees with diabetes and 76% of Medicaid managed care enrollees with diabetes received at least one hemoglobin A1C test. There has been a 3% to 4% annual increase of the testing rate since 1998. (QARR 2000)



- In 2000, 58% of commercial managed care enrollees with diabetes and 49% of Medicaid managed care enrollees with diabetes received a dilated eye exam, representing an increase from the previous year (57% and 40%, respectively). (QARR 2000)
- In 2000, 84% of commercial managed care enrollees with diabetes and 68% of Medicaid managed care enrollees with diabetes received a lipid profile test, almost a 10% increase from the previous year (78% and 57%, respectively). (QARR 2000)
- In 2001, 52% of people with diabetes reported that they had a flu shot in the previous 12 months. The proportion of people with diabetes who had a flu shot was 49% in 1997 (BRFSS 2001)
- In 2001, 56% of people with diabetes reported that they check blood glucose levels at least once a day. The rate was 44% in 1997. (BRFSS 2001)
- In 2001, 48% of people with diabetes took aspirin every day or every other day for cardiovascular health. The rate is an increase since 1999 when only 31% did the same. (BRFSS 2001)

## New York State Programs for Diabetes

New York State was one of the seven states that received the first diabetes control program core funding from the CDC in 1977. Since 1977, the state and the CDC have developed a collaborative relationship in many diabetes control activities, particularly prevention of complications. During its early years, the state diabetes program focused on assessment of regional-level diabetes care resources and patient/provider education. During the late 1980s, the program conducted statewide eye care surveys of ophthalmologists, optometrists, and primary care physicians to assess the use of laser treatment for diabetic retinopathy (new technology at that time). In 1992, the St. Regis-Mohawk Coalition Risk Reduction Project was launched to increase diabetes awareness and screening among Native Americans. From 1994 to 1997, a Diabetes Minority Initiative project was conducted to improve diabetes care standards in health care facilities serving minority populations. In 1998, New York State became a “comprehensive” funded state, and in 2001, the state diabetes control program changed its name to Diabetes Prevention and Control Program (DPCP) to reflect its new emphasis on primary prevention of diabetes. Program funding from the state sources, including the Commissioner’s Priority Pool, and allocations of the Preventive Health and Health Services Block Grant, a consistent state appropriation, and research funding from the Association of Schools of Public Health helped the diabetes program to grow.

Currently, the DPCP operates in three major areas: Surveillance and Evaluation, Community Initiatives, and Quality Improvement. Adopting the national objectives set by the CDC, the DPCP has sponsored and/or supported through funding or partnership a multitude of programs including:

- Thirteen (13) Community Coalitions for Diabetes Prevention to implement community-based diabetes prevention and control activities. Their activities are monitored and evaluated continuously through participant encounter data and monthly activity logs.
- Three (3) Diabetes Centers of Excellence to develop and disseminate tools for high quality diabetes primary and specialty care in clinical settings. The centers also engage diabetes professional education, outreach and community-oriented programs.

- Four (4) pilot projects for the Governor's Initiative for Children with Diabetes to address diabetes-related children's issues in schools and with community groups.
- Diabetes-related projects at the Prevention Research Center of the University at Albany School of Public Health. The Prevention Research Center and the DPCP are collaborating in research and intervention projects to address diabetes care and management barriers in local disadvantaged communities.
- Surveys to assess diabetes prevalence, risk factors, and status of diabetes care among hard-to-reach minority communities. Puerto Ricans in New York City and Japanese in Westchester County were surveyed using innovative sampling methods.
- State-specific activities of the national-level programs, including flu and pneumococcal vaccination campaigns and the National Diabetes Education Program.
- New York Health Plan Association's Westchester New York Diabetes Initiative, which brings together a multitude of partners in an effort to improve disease prevention practices among providers and patients with diabetes.
- Collection of data from federally funded Health Disparities Diabetes Collaboratives projects, and offering resources, information, and support to them.
- Collaboration with other programs within the Department of Health including the AIDS Institute on the Expanded Syringe Access Program (ESAP), and diabetes care quality assurance activities with the Office of Medicaid Management and the Office of Managed Care.

Like the federal-level diabetes programs, the New York State DPCP continues to work toward the reduction of diabetes-related morbidity, disability, and mortality. Promotion of primary, secondary, and tertiary prevention, and closing the disparities in the burden of diabetes are priority areas. With increasing numbers of elderly and disadvantaged minority populations, the DPCP expects more challenges ahead. Combining resources from our partners and stakeholders, the DPCP will continue to build program and research capacities in these priority areas.

In September 2000, the New York State Department of Health Diabetes Prevention and Control Program called together a representative group of diabetes experts and stakeholders from across the state to form the New York State Diabetes Task Force. The Task Force was charged with addressing the needs of people with and at risk for diabetes statewide. A major focus of the Task Force has been the ongoing development of the New York State Plan for the Prevention and Control of Diabetes. The New York State Plan reflects areas of greatest priority: Provider and Public Education, Prevention of Diabetes and Diabetes Related Complications, Health Insurance/ Managed Care/ Quality Assurance, Children and Diabetes, and Public Health Tracking and Evaluation.

Francine Haddad, a Regional Advocacy Director for the American Diabetes Association, served as the facilitator for the development of the New York State Plan. With her guidance, the above-mentioned workgroups were established in June 2002 at a face-to-face meeting of the Task Force. Numerous meetings and conference calls of the topical subgroups occurred during the summer and early fall, culminating in the development of draft plans for the final document, which included goals and action steps. The Task Force was reconvened in October 2002 to gather feedback on the draft document. The finalized New York State Plan for the Prevention and Control of Diabetes was included in New York State's competitive application to the Centers for Disease Control and Prevention for diabetes funds, awarded in April 2003.

The Task Force will continue to meet on a regular basis to refine the goals and proposed action plans and to evaluate progress toward this accomplishment. The Task Force will advise the New York State Department of Health on this and related issues.

A description of the priority areas identified by the Task Force follows.

## **A. PROVIDER AND PUBLIC EDUCATION**

### **Background**

Increasing awareness of the seriousness of diabetes through collaboration with community partners, media campaigns (National Diabetes Education Program, Life Preserver Diabetes/Flu campaign), and incorporating research findings will allow people with diabetes to better manage their disease and support behavior change.

The Diabetes Prevention Program (DPP) and other research studies have shown that obesity and a sedentary lifestyle are modifiable risk factors for people with or at risk for type 2 diabetes. Additionally, recent evidence indicates that people with pre-diabetes will likely go on to develop type 2 diabetes within 10 years, unless they make modest changes in their diet and level of physical activity. Educational materials for the public and health care providers should focus on increasing knowledge about risk factors, and promoting physical activity and healthy eating to prevent diabetes. For people with diabetes, campaigns directed toward self-management and lifestyle changes are effective methods to achieve better health outcomes.

### **Problem Statement**

There is a general lack of awareness among health care professionals and the public about the implications of studies showing that lifestyle changes can prevent or delay the onset of diabetes and complications of diabetes. Diabetes management guidelines recommended by the American Diabetes Association and others are not always utilized as the standard of care by health care providers.

### **Goals and Proposed Actions**

The primary goal identified by the Task Force is to promote increased awareness of the prevention and control of diabetes and its complications by providing consistent messages to the public and providers. Strategies identified to accomplish this goal include:

- Increase awareness of the signs and symptoms of diabetes.
- Provide current, consistent information on diabetes risk factors, prevention and treatment.
- Develop and disseminate culturally appropriate educational materials and messages.
- Standardize provider training using current clinical practice guidelines.
- Incorporate national media campaigns into messages and materials.
- Develop low literacy materials.
- Translate new research findings on lifestyle changes into practical recommendations that can prevent or control diabetes in individuals at risk of developing this disease or those who could experience complications of uncontrolled diabetes.
- Work with sponsors of educational workshops and training sessions to offer health care providers and health care professionals continuing education units.

## B. PREVENTION OF TYPE 2 DIABETES AND DIABETES-RELATED COMPLICATIONS

### Background

Diabetes is one of the most costly and burdensome chronic diseases of all time, affecting approximately eight percent (18 million) of adults in the United States. Complications that can result from poorly managed diabetes represent a significant cause of morbidity and mortality and include heart disease, stroke, blindness, kidney failure, leg and foot amputations, pregnancy complications, and deaths related to flu and pneumonia. The direct and indirect costs of diabetes have been estimated at nearly \$132 billion per year nationally.

New estimates indicate that up to 37 million American adults have pre-diabetes, a condition in which blood glucose levels are higher than normal but are not high enough for a diagnosis of diabetes. People with pre-diabetes are at increased risk for developing type 2 diabetes and for heart disease and stroke. Over the past decade, primary prevention research studies in the United States and abroad have demonstrated that modest lifestyle changes can prevent or delay the onset of type 2 diabetes among high-risk adults. Lifestyle interventions included dietary changes to induce weight reduction and moderate-intensity physical activity (such as walking for 2 1/2 hours each week). For both sexes and all ages, ethnic and racial groups studied, the development of diabetes was reduced up to 60% during these studies that lasted three to six years.

Given the high cost of diabetes complications and the new information available on the success of primary prevention efforts, it is more important than ever to promote healthy lifestyles, compliance with clinical practice guidelines and improved access to health care services in order to prevent diabetes and delay its progression once diagnosed.

### Problem Statement

According to the most recent National Health and Nutrition Examination Survey III (1999 – 2000), nearly one in every three American adults is now obese and almost two-thirds are overweight. The number of overweight and obese people continues to rise despite the fact that Americans spend \$34 billion on weight management products and services each year.

The U.S. Surgeon General has declared obesity in children and adolescents in the United States epidemic. Some of the reasons for this trend are a lack of physical activity and the increased consumption of fast foods that are high in calories and fat. The more overweight children are, the greater is their risk of developing diabetes. Adolescents are being diagnosed with type 2 diabetes at an alarming rate.

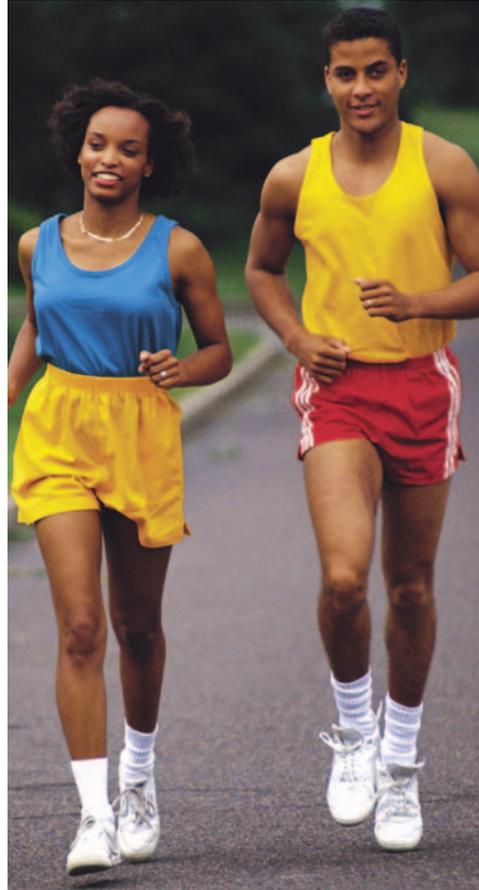
Diabetes prevention efforts should encompass the various behavioral, environmental and societal factors that have contributed to the increased trends in risk factors for diabetes and its complications at all age levels.

### Goals and Proposed Actions

The Task Force has identified as its primary goal in this area to work in collaboration with other chronic disease prevention efforts and initiatives and, using proven science, to promote healthy lifestyles and diabetes disease management (including self-management) across the lifespan to prevent diabetes and its complications.

Activities identified to implement this goal would reach a diverse audience of providers, patients, communities, and the health care system. They include plans to:

- Develop and implement programs for primary care practitioners designed to increase their awareness of diabetes standards of care and proven methods for diabetes prevention.
- Promote educational opportunities for patients with and at risk for diabetes.
- Support environmental changes within communities that will be conducive to healthy lifestyles.
- Develop and disseminate educational materials aimed at prevention messages for all age groups from pre-school to seniors.
- Educate policymakers regarding the benefit of adequate insurance coverage for patient education, including improved quality of life and patient care, and cost savings.
- Promote regular physical activity and good nutrition in schools.



## C. QUALITY ASSURANCE

### Background

Studies such as The United Kingdom Prospective Diabetes Study (UKPDS), the Diabetes Control and Complications Trial (DCCT), the Hypertension Optimal Treatment (HOT) Study, the Heart Outcomes Prevention Evaluation (HOPE) Study, the 4S Study and the Cholesterol and Recurrent Events Trial (CARE Study) have shown that tighter control of glucose levels, better control of blood pressure and lowering of lipid levels lead to delays or avoidance of diabetes complications. Self-management of diabetes by patients with support from a health care team is a strong contributor to tighter control. Advances in diabetes-related technology and medical treatment have allowed individuals with diabetes to become important partners on their health care teams. Individuals with diabetes need to understand the complexity of managing the effects of glucose, blood pressure, lipids, nutrition, physical activity and mental well being to prevent or delay complications such as heart disease, blindness, lower limb amputation and end-stage renal disease.

As part of the team approach, persons with diabetes benefit greatly from Diabetes Self Management Education (DSME), which, according to the American Association of Diabetes Educators, is defined as an interactive, collaborative, ongoing process involving the person with diabetes and the certified diabetes educator(s) (CDE). This process includes (1) assessment of the individual's specific education needs; (2) identification of the individual's specific diabetes self-management goals; (3) education and behavioral interventions directed toward helping the individual achieve identified self-management goals; and (4) evaluation of the individual's attainment of identified self-management goals. Translating this definition into practice, DSME is intended to assist people with diabetes design their own self-management treatment plan in consultation with a variety of health care professionals such as doctors, nurses, dietitians, pharmacists and others specifically trained to provide DSME. The training includes meal planning, planned physical activity, blood glucose monitoring, taking diabetes medicines,

handling diabetes while traveling, sick day management and many other aspects of their care. Since self-management is an ongoing process, one goal of DSME is to assist people with diabetes in coping with the life long challenges created by this disease, in an effort to prevent complications.

Individuals also receive instructions and support in using the latest technical innovations in diabetes monitoring and care. Diabetes-related technology includes insulin in its many variations, insulin pumps, glucometers, numerous oral medications and innovative drug therapies that allow the treatment of diabetes to more closely mimic the actions of endogenous insulin. In an attempt to standardize the information presented in DSME programs, the American Diabetes Association (ADA) awards an Education Recognition Program (ADA-ERP) certification to providers and facilities that meet nationally recognized criteria and standards. Providers and facilities offering DSME programs are strongly encouraged to seek ADA-ERP certification in order to participate in insurance programs that reimburse for DSME (e.g., Medicare). Not all insurance programs offer this benefit to their enrollees.

All these revolutionary educational and innovative prospects, unfortunately, have not produced a cure for diabetes but have provided opportunities to more closely control diabetes and delay the onset or severity of complications. The escalating cost of equipment, supplies and DSME have created a challenge for people with diabetes to keep up with these improvements in care.

Many people with diabetes who have insurance received relief from the increasing costs of managing their disease as a benefit of the Diabetes Insurance Law, passed in 1993 (effective in 1994). The law applies to all health maintenance organizations, health insurance policies which provide comprehensive or major medical coverage and health insurance policies which cover outpatient services performed in a physician's office. It mandates coverage for diabetes education and various diabetes equipment and related supplies. The equipment and related supplies include, but are not limited to: urine and blood testing equipments for the majority of New Yorkers (lancets, test strips, monitors), pharmaceuticals (all insulin preparations and oral anti-diabetic agents to reduce blood sugar levels), medication delivery systems and devices (insulin pumps, syringes, infusion devices), related supplies (alcohol swabs, control solutions for monitors), equipment for the use of insulin pumps, oral agents and glucagon for the treatment of hypoglycemia and miscellaneous supplies.

Many New York residents are enrolled in entitlement programs, such as Medicaid, which provide coverage for a myriad of services, supplies and health related equipment. Benefits of this program include physician and clinic visits, hospitalization, durable medical equipment, prescription and non-prescription medications, blood and urine testing supplies, sick room supplies, smoking cessation products and numerous other supplies and services. Almost three million New Yorkers below the age of 65 (17% of all New York residents) remain uninsured, thus lacking access to necessary supplies and services. According to the Agency for Healthcare Research and Quality's 1998 Medical Expenditure Panel Survey (MEPS), Blacks and Hispanics are more likely than whites to be uninsured and less likely to have employer-sponsored health coverage.

## Problem Statement

There are a number of issues related to quality of care and inadequate insurance coverage for large segments of the population with diabetes:

- A large number of people with diabetes still experience devastating complications even with the encouraging findings of recent studies highlighting the benefits of nutrition, physical activity and good disease management.

- Many individuals are not covered by the Diabetes Insurance Law. The law does not cover uninsured individuals, Medicaid recipients, Medicare or Medigap beneficiaries, employer-sponsored benefits plans that are self-insured, union-sponsored benefit plans including public employees, plans which insure employees in more than one state and health insurance policies which were not issued in New York State.
- Currently there is a lack of a distinct method of reimbursement for Diabetes Self-Management Education (DSME) for individuals with diabetes enrolled in many insurance plans and for all individuals without health care benefits.
- It is difficult to assess the quality of care being provided to people with diabetes given the large number of insurers and the lack of a diabetes registry.

## Goals and Proposed Actions

The Task Force has identified the need to improve primary and specialty care for diabetes management and prevention as a major goal. To achieve this goal, the Task Force has proposed the following actions to ensure that all New Yorkers have access to diabetes equipment, related supplies and education:

- Educate policymakers regarding the benefit of broadening the categories of individuals covered by the Diabetes Insurance Law.
- Develop methodologies to be used by health care payers to assess quality of care.
- Develop and disseminate education materials and provide increased training opportunities for health care providers on the diabetes standards of care.
- Work toward adding distinct reimbursement for Diabetes Self-Management Education (DSME) to the list of services provided by all insurers in New York State.

## D. CHILDREN AND DIABETES

### Background

New York's children represent New York's future. Healthy children are vital for a healthy New York. Presently, type 1 diabetes is the second leading childhood chronic disease affecting at least 13,000 children in New York. Anecdotal information indicates that the rate of type 1 diabetes may be increasing. The majority of children with diabetes have type 1, but the incidence of type 2 diabetes, which typically has an adult onset, continues to increase at alarming rates. Type 2 diabetes usually develops in adults over age 45, but has become increasingly common among children and adolescents. This trend has health professionals gravely concerned. Currently there are no reliable estimates of the prevalence of type 2 diabetes among children in New York State, although anecdotally, pediatric endocrinologists report that one of three new cases in adolescence is type 2 diabetes. It is believed that these estimates are low and that there are unknown numbers of undiagnosed or misdiagnosed cases of type 2 diabetes in adolescents.

Over the last two decades the number of overweight children in the United States has doubled. Upwards of 15% of U.S. children are now overweight and recently the U.S. Surgeon General declared obesity "epidemic" in children. It is believed that changes in American culture such as increased sedentary lifestyle and unhealthy food choices are partially to blame for this disturbing public health trend. The medical community agrees; the more overweight children become, the greater the chance they have of developing type 2 diabetes. Those most at risk include children of Native American, African American and Hispanic origins.



## Problem Statement

Because of the growing number of school-age children with diabetes, the effects of diabetes upon a student's ability to attend school and learn, and the risk of serious long-term medical complications, it is essential that schools provide a safe and health-conscious environment for children with and at-risk for diabetes. Schools provide the opportunity to reach young people, educators, administrators, and the school healthcare personnel who serve them; however, they currently do not provide consistent opportunities for adequate physical activity and proper nutrition, and education for both the prevention and management of chronic disease. Schools lack knowledgeable and well-trained staff to ensure the immediate safety of children with diabetes requiring emergency administration of glucagon for the treatment of dangerously low blood sugar. Additionally, it is a challenge for schools to provide supportive environments so that children with diabetes can participate fully in the school experience. Reaching children, families and those who interact with them to assure comprehensive, continuing and individualized diabetes care and prevention is essential.

There are federal laws that protect children with diabetes including section 504 of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act of 1991 and the Americans with Disabilities Act of 1990. These federal laws require development of an individualized assessment of any child with diabetes and provision of reasonable accommodation to allow a child's full participation in all school activities. Despite these protections, children with diabetes continue to face discrimination and encounter increasing difficulty in participating fully in activities and managing their diabetes in school. Appropriate diabetes care in the school setting is necessary for the child's immediate safety, long-term well-being and optimal academic performance.

## Goals and Proposed Actions

The Task Force has identified two distinct goals in this area. The first is the need to make schools safe for children with diabetes. To accomplish this goal, the Task Force has recommended the following strategies:

- Disseminate consensus guidelines as available for type 1 and type 2 diabetes to ensure that the child's standard of care is maintained at school.

- Educate primary health care providers on school diabetes care and applicable state and federal legislation.
- Provide pre-service and in-service training for school personnel.
- Enhance primary prevention efforts for type 2 diabetes through school food service and physical activity initiatives.
- Ensure that school personnel are aware of all policies related to children with diabetes.
- Encourage the development of individual medical management plans for all students with diabetes.
- Support efforts to create uniform school healthcare forms for children with diabetes.

The second goal is to more accurately quantify the prevalence and incidence of diabetes and diabetes risk in children in New York State. To achieve this goal, the Task Force has recommended:

- Creation of a public health diabetes registry for children to increase New York’s knowledge about the epidemiology of diabetes in children, and address the great need for a population-based surveillance system.
- Supportive efforts to obtain aggregated height/weight measures on children, particularly grades K – 8, as measures of diabetes risk, based on overweight or obesity.

## E. PUBLIC HEALTH TRACKING AND EVALUATION

### Background

The Diabetes Task Force of New York State recognizes the primary importance of collecting and documenting information on diabetes prevalence and incidence, demographic information about people with diabetes and factors surrounding their health as it relates to diabetes. Numerous data sources provide information related to these issues. Data sources include but are not limited to:

(1) The New York State Behavioral Risk Factor Surveillance System (BRFSS), a population-based telephone survey developed by the Centers for Disease Control and Prevention (CDC) and administered by the New York State Department of Health; (2) the Statewide Planning and Research Cooperative System (SPARCS), a comprehensive hospital patient data system established in 1979 as a result of cooperation between the health care industry and government; (3) Vital Records from the Bureau of Production Systems Management, New York State Department of Health which processes data from birth, death and marriage certificates; (4) End-Stage Renal Disease Network (ESRDN) which is under contract with the Centers for Medicare and Medicaid Services (CMS) to track patients on renal dialysis in New York State. (5) Youth Risk Behavior Survey (YRBS)



Collectively, these data sources have been used by the New York State DPCP to estimate diabetes-related mortality, prevalence of diabetes among adults, prevalence of diabetes complications in hospitalized patients as well as the prevalence of diabetes-related behavioral risk factors in youths. No data sources currently exist that could potentially be used to estimate the incidence of diabetes in New York State. Similarly, data for estimating the incidence and prevalence of diabetes in children and adolescents are also lacking.

## **Problem Statement**

Little is known about the extent of barriers to optimal diabetes care as well as the extent of emergency room use among New Yorkers with diabetes. Recent research findings have refocused attention on the assessment of the impact of language and literacy-related barriers on diabetes outcomes. Literacy-related barriers include the inability to read and comprehend medical instructions. Populations that commonly experience literacy-related barriers to adequate medical care include immigrant, racial/ethnic minority, low-income, elderly and rural populations. New York State has growing populations that fall under these high-risk groups for inadequate diabetes care. Persons with diabetes who do not have access to timely and adequate care are at increased risk of diabetes complications, including retinopathy, neuropathy and lower extremity amputations.

## **Goals and Proposed Actions**

The Task Force has identified as its primary goal in this area the assessment and monitoring of barriers to diabetes care in New York State. Issues related to diabetes care include language/literacy barriers, emergency room utilization, and differences in diabetes care sought and rendered in diverse communities, rural and urban areas, or upstate and downstate regions. The new focus on the monitoring of barriers to diabetes care throughout the State will not be pursued exclusively but will augment ongoing surveillance efforts. Activities identified to meet this goal include:

- Assess and track the prevalence of language/literacy barriers and their impact on diabetes care in New Yorkers with diabetes, including special populations.
- Assess and track the extent of Emergency Room use for routine, urgent, and emergent care among New Yorkers with diabetes.
- Assess and track differences in patterns of care in various types of organizations and across the diverse communities of New York State.

## References

American Diabetes Association: Standards of medical care for patients with diabetes mellitus. *Diabetes Care* 1989;12:365-368

American Diabetes Association: Care of Children with Diabetes in the School and Day Care Setting. *Diabetes Care* 2002; 25:S122-S126

Diabetes Prevention Program Research Group. Reduction in the incidence of type 2 diabetes with lifestyle intervention or Metformin. *N Eng J Med* 2002; 346:393-403

The Diabetes Control and Complications Trial Research Group: The effect of intensive treatment of diabetes on the development and progression of long-term complications in Insulin-Dependent Diabetes Mellitus. *N Eng J Med* 1993;329:977-986

The Expert Committee on the Diagnosis and Classification of Diabetes Mellitus: Report of the Expert Committee on the diagnosis and classification of Diabetes Mellitus. *Diabetes Care* 1997;20:1183-1197.

Flegal KM, Carroll MD, Ogden CL, Johnson CL. Prevalence and trends in obesity among US adults, 1999-2000. *JAMA* 2002; 288:1723-1727

Fleming BB, Greenfield S, Engelgau MM, Pogach LM, Clauser SB, Parrott MA (the DQIP Group). The Diabetes Quality Improvement Project: moving science into health policy to gain an edge on the diabetes epidemic. *Diabetes Care* 2001; 24:1815-1819

Ford ES, Giles WH, Dietz WH. Prevalence of the metabolic syndrome among US adults. *JAMA* 2002; 287; 356-359

Gray A, Raikou M, McGuire A, Fenn P, Stevens R, Cull C, Stratton I, Adler A, Holman R, Turner R: Cost effectiveness of an intensive blood glucose control policy in patients with type 2 diabetes: economic analysis alongside randomised controlled trial (UKPDS 41). *BMJ* 2000;320:1373-1378

Hahn RA, Teutsch SM, Rothenberg RB, Marks JS. Excess deaths from nine chronic diseases in the United States, 1986. *JAMA* 1990;264:2654-2659.

Hansson L, Zanchett A, Carruthers SG et al. Effects of intensive blood pressure lowering and low-dose aspirin on patients with hypertension: principal results of the Hypertension Optimal Treatment (HOT) randomized trial. *Lancet* 351: 1755-1762, 1998

Heart Outcomes Prevention Evaluation (HOPE) Study Investigators. Effects of ramipril on cardiovascular and microvascular outcomes in people with diabetes mellitus: results of the HOPE study and MICRO-HOPE study. *Lancet* 355: 253-259, 2000

Mokdad AH, Bowman, BA, Ford ES, Vinicor F, Marks JS, Koplan JP. The Continuing Epidemics of Obesity and Diabetes in the United States. *JAMA* 2001; 286:1195-1200

Mokdad AH, Ford ES, Bowman BA, Nelson DE, Engelgau MM, Vinicor F, Marks JS. Diabetes trends in the U.S.: 1990-1998. *Diabetes Care* 2000;23:1278-1283.

Mokdad AH, Serdula MK, Dietz WH, Bowman BA, Marks JS, Koplan JP. The spread of the obesity epidemic in the United States, 1991-1998. *JAMA* 1999;282:1519-1522

The National Heart, Lung, and Blood Institute Obesity Education Initiative Expert Panel . On the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults. Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults: the Evidence Report. The National Institute of Health, National Heart, Lung, and Blood Institute, Bethesda, MD. 1998.

National Institute of Health. Third Report of the National Cholesterol Education Program Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III. Bethesda, MD. National Institute of Health; 2001. NIH Publication 01-3670

Ogden CL, Flegal KM, Carroll MD, Johnson CL. Prevalence and Trends in Overweight Among US Children and Adolescents, 1999-2000. *JAMA* 2002; 288: 1728-1732.

Pan XR, Li GW, Hu YH, Wang JX, Yang WY, An ZX, Hu ZX, Lin J, Xiao JZ, Cao HB, Liu PA, Jiang XG, Jiang YY, Wang JP, Zheng H, Zhang H, Bennett PH, Howard BV. Effects of diet and exercise in preventing NIDDM in people with impaired glucose tolerance. The Da Qing IGT and Diabetes Study. *Diabetes Care* 1997;20:537-544

Pyorala K, Pedersen TR, Kjekshus J, Faergeman O, Olsson AG, Thorgeirsson G. Cholesterol lowering with simvastatin improves prognosis of diabetic patients with coronary heart disease: a subgroup analysis of the Scandanavian Simvastatin Study (4S). *Diabetes Care* 20: 614-620, 1997

Sacks FM, Pfeffer MA, Moye L, et al. Rationale and design of a secondary prevention trial of lowering normal plasma cholesterol levels after acute myocardial infarction: the Cholesterol and Recurrent Events trial (CARE). *Am J Cardiol* 1991; 68:1436-1446. [Erratum, *J Cardiol* 1992; 69:574.]

Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, Palacios, Diaz, Sullivan G, Bindman AB. Association of health literacy with diabetes outcomes. *JAMA* 2002; 288:475-482.

Tuomilehto J, Lindstrom J, Eriksson JG, Valle TT, Hamalainen H, Ilanne-Parikka P, Keinanen-Kuikkaanniemi S, Laakso M, Louheranta A, Rastas M, Salminen V, Uusitupa M: Prevention of type 2 Diabetes Mellitus by changes in lifestyle among subjects with impaired glucose tolerance. *N Eng J Med* 2001;344:1343-1350

UK Prospective Diabetes Study (UKPDS) Group: Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). *Lancet* 1998;352:837-853

UK Prospective Diabetes Study (UKPDS) Group: Effect of intensive blood-glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34). *Lancet* 1998;352:854-865

UK Prospective Diabetes Study (UKPDS) Group: Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes (UKPDS 38). *BMJ* 1998;317:703-713

Youdelman M, Perkins J. Quality of Care in Underserved Populations. Providing Language Interpretation Services in Health Care Settings: Examples from the Field. The Commonwealth Fund Field Report. The Commonwealth Fund: New York, 2002.

|  |  |                                    |   |
|--|--|------------------------------------|---|
| Michael A. Acosta                      | Health Program Administrator NYSDOH<br>Office of Minority Health   | Thomas Schumacher                  | Capital District Renal Physicians/Nephrology  |
| Jo Ann Bennisson                       | New York Association of County Health Officials  | Pamela Selover                     | Consumer  |
| Sam F. Berardino, R. Ph.               | Public Health System Specialist<br>Eli Lilly and Company   | Judith A. Siler, MS, RD, CDE, CDN  | St. Peter's Hospital, Albany NY   |
| Diana K. Berger, MD, MSc               | Director, Diabetes Prevention and Control Program<br>New York City Department of Health and<br>Mental Hygiene                                  | Susan Slade RN, MS, CHES           | Public Health Program Nurse<br>Children with Special Health Care Needs Program  |
| Larry Bjurstrom, PhD                   | Healthy State Wellness Program   | Denise Spor, B.A., R.N.            | NYS Department of Health<br>Office of Medicaid Management   |
| Sara Bonam, MS, RD                     | Nutrition Advocate<br>Office of Local Health Services<br>New York State Dept. of Health  | Sue Ellen Wagner                   | Hospital Association of New York State  |
| Kathy M. Brieger, MA, RD, CDE          | Diabetes Collaborative Representative<br>Hudson River Community Health   | Elizabeth A. Walker, DNSc, RN, CDE | Associate Professor of Medicine<br>Director, Prevention and Control Component<br>The Diabetes Research and Training Center<br>Albert Einstein College of Medicine |
| William R. Calnon, DDS                 | NYS Dental Association   | Ruth Weinstock, MD                 | Joslin Diabetes Center<br>SUNY – Upstate Medical Center, Syracuse   |
| Margaret O. Casey, RN, MPH             | Director, Healthy Heart Program<br>NYS Department of Health  | David Whitehead                    | Bristol-Myers Squibb Company  |
| Hiram Chirel, DPM                      | Executive Director<br>New York State Podiatric Medical Association   | Andrea Zaldivar MS, ANP, CDE       | Clinical Coordinator Diabetes Care IMA<br>Mt. Sinai Medical Center  |
| Joan E. Clifford                       | Senior Area Director<br>American Diabetes Association  |                                    |   |
| James Desemone, MD, FACE               | Director, Goodman Diabetes Service<br>Associate Professor of Medicine<br>Albany Medical Center   |                                    |   |
| Jack Devore, O.D.                      | Optometrist  |                                    |   |
| Jamie Dollahite, PhD, RD               | Associate Professor of Community Nutrition<br>Cornell Cooperative Extension  | Elizabeth Berberian, MPH           | Assistant Director<br>Bureau of Chronic Disease Services  |
| Cristina Dyer-Drobneck                 | New York State Association of County Health Officials  | David P. Hoffman, M.Ed             | Director<br>Bureau of Chronic Disease Services  |
| Kim Farquharson                        | Project Coordinator<br>New York Health Plan Association  | Rita Fahr, MPH, RPH                | Director, Quality Improvement Initiatives<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services  |
| Robin S. Goland, MD                    | Co-Director<br>Naomi Berrie Diabetes Center<br>Irving Associate Professor of Medicine<br>Columbia University                                   | Patricia Gutierrez, BA             | Public Health Representative<br>Bureau of Chronic Disease,<br>Epidemiology and Surveillance   |
| Herbert B. Gordon                      | Gordon & Gordon Associates, Inc.   | Akiko Hosler, Ph.D.                | Director, Diabetes Surveillance and Evaluation<br>Bureau of Chronic Disease,<br>Epidemiology and Surveillance   |
| Francine Haddad                        | American Diabetes Association  | Stan Mathews                       | Administrative Support<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services   |
| Beverly Kennedy                        | Juvenile Diabetes Research Foundation  | Susan Millstein, CSW               | Technical Advisor<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services  |
| Patricia T. King, MPH, CASAC           | Project Manager<br>Health Care Quality Improvement<br>IPRO   | Jackson Sekhobo, MPA               | Research Scientist II-<br>Diabetes Surveillance and Evaluation<br>Bureau of Chronic Disease,<br>Epidemiology and Surveillance                                     |
| Peggy Leonard                          | NY Health Plan Association   | Laura Shea, RN                     | Professional and Public Education Coordinator<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services                                    |
| Daria Luisi, Ph.D., MPH                | Director<br>Health Promotion & Disease Prevention Program<br>New York City Dept of Health & Mental Hygiene                                     | Maureen Spence, MS, RD             | Coordinator<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services  |
| Robert S. Luria                        | Executive Manager<br>State Government Affairs<br>Glaxo-Smith Kline   | Louise Square                      | Technical Advisor<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services  |
| Catherine Marschilok, MSN, CDE, BC-ADM | Director of Diabetes Services<br>Northeast Health  | Eric Weiskopf, M.Ed                | Program Assistant<br>Diabetes Prevention and Control Program<br>Bureau of Chronic Disease Services  |
| Joyce Novak, RN, MS                    | NYSDOH<br>Office of Managed Care   |                                    |   |
| Daryl Patterson                        | New York State Health Plan Association   |                                    |   |
| Robert Rapaport, MD                    | Emma Elizabeth Sullivan Professor and Director<br>Division of Pediatric Endocrinology and Diabetes<br>Mt. Sinai School of Medicine             |                                    |   |
| Holly Schachner, MD                    | Assistant Professor of Clinical Pediatrics<br>Assistant Director for Pediatric Diabetes<br>Naomi Berrie Diabetes Center at Columbia University |                                    |   |

## New York State Department of Health Diabetes Staff Members