

## Chapter 5

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# Diabetes

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Diabetes mellitus (diabetes) is a prevalent, costly condition that causes significant illness, disability, and premature death. An estimated 15.7 million people (5.9% of the total U.S. population) have diabetes,<sup>1</sup> of whom 5.4 million are undiagnosed. In 1997 alone, 789,000 new cases were diagnosed.<sup>1</sup> Moreover, according to 1996 death certificates, diabetes is the seventh leading cause of death in the United States.<sup>1</sup> The costs of diabetes to the American healthcare system are enormous, with total (direct and indirect) costs estimated at \$98 billion in 1997.<sup>2</sup>

Our systematic reviews focused on population-based strategies to improve the care of people with either type 1 or type 2 diabetes. (Type 1 diabetes results from destruction of the  $\beta$ -cells of the pancreas, and type 2 is charac-

\*Insufficient evidence means that we were not able to determine whether or not the intervention works.

The Task Force approved the recommendations in this chapter in 2000–2001. The research on which the findings are based was conducted between 1966 and December 2000. This information has been previously published in the American Journal of Preventive Medicine (2002; 22[4S]:10–14, 15–38, and 39–66) and the MMWR Recommendations and Reports (2001; 50[No. RR-16]:1–15).

terized by insulin resistance and relative insulin deficiency.<sup>3</sup>) The interventions reviewed were conducted both in healthcare systems and in community settings.

## **OBJECTIVES AND RECOMMENDATIONS FROM OTHER ADVISORY GROUPS**

Reducing illness, disability, and premature death and improving the quality of life for people with diabetes is a major public health objective. *Healthy People 2010*<sup>4</sup> objectives have been set to prevent diabetes, increase early diagnosis, improve rates of screening for its complications, and decrease morbidity and mortality. Objectives that address issues specifically covered in this chapter are shown in Table 5–1.

Recommendations for clinical care of persons with diabetes can be obtained from the American Diabetes Association (ADA),<sup>5</sup> and screening recommendations are available from the U.S. Preventive Services Task Force's *Guide to Clinical Preventive Services*.<sup>6</sup>

## **METHODS**

Methods used for the reviews are summarized in Chapter 10. Specific methods used in the systematic reviews of diabetes have been described elsewhere<sup>7</sup> and are available at [www.thecommunityguide.org/diabetes](http://www.thecommunityguide.org/diabetes). The analytic frameworks depicting the conceptual approach used in the reviews are presented in Figures 5–1 and 5–2.

## **ECONOMIC EFFICIENCY**

A systematic review of available economic evaluations was conducted for all recommended interventions, and a summary of each review is presented with the related intervention. The methods used to conduct these economics reviews are summarized in Chapter 11.

## **RECOMMENDATIONS AND FINDINGS**

This section presents a summary of the findings of the systematic reviews conducted to determine the effectiveness of the selected interventions in this topic area. We reviewed two interventions appropriate for use in healthcare systems (disease management and case management) and five situations in which diabetes self-management education (DSME) may be appropriate (in community gathering places, in the home, in summer camps, at the worksite, and in the education of school personnel).

**Table 5–1.** *Healthy People 2010*<sup>4</sup> Objectives for Improving Diabetes Outcomes

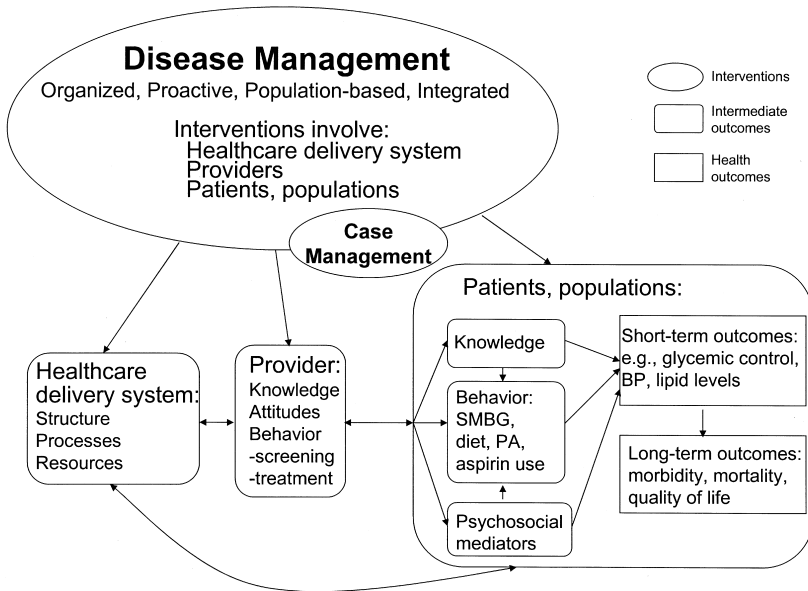
<i>Objective</i>	<i>Population</i>	<i>Baseline</i>	<i>2010 Objective</i>
Increase the proportion of persons with diabetes who receive formal diabetes education (Objective 5–1)	All diabetics	45% (1998 <sup>a</sup> )	60%
Reduce the frequency of foot ulcers in persons with diabetes (5–9)	All diabetics	Developmental	
Reduce the rate of lower extremity amputations per 1000 persons with diabetes (5–10)	All diabetics	4.1% (1997 <sup>a</sup> )	1.8
Increase the proportion of persons with diabetes who obtain an annual urinary microalbumin measurement (5–11)	All diabetics	Developmental	
Increase the proportion of adults $\geq 18$ years with diabetes who have a glycosylated hemoglobin measurement at least once a year (5–12)	Adult diabetics	24% (1998 <sup>a,b</sup> )	50%
Increase the proportion of adults $\geq 18$ years with diabetes who have an annual dilated eye examination (5–13)	Adult diabetics	47% (1998 <sup>a</sup> )	75%
Increase the proportion of adults $\geq 18$ years with diabetes who have at least an annual foot examination (5–14)	Adult diabetics	55% (1998 <sup>a,b</sup> )	75%
Increase the proportion of adults $\geq 40$ years with diabetes who take aspirin at least 15 times per month (5–16)	Adult diabetics	20% (1988–94 <sup>a</sup> )	30%
Increase the proportion of adults $\geq 18$ years with diabetes who perform blood-glucose self-monitoring at least once daily (5–17)	Adult diabetics	42% (1998 <sup>a,b</sup> )	60%

<sup>a</sup>Age adjusted to the year 2000 standard population.

<sup>b</sup>Mean of data from 39 states.

### **Healthcare System Interventions**

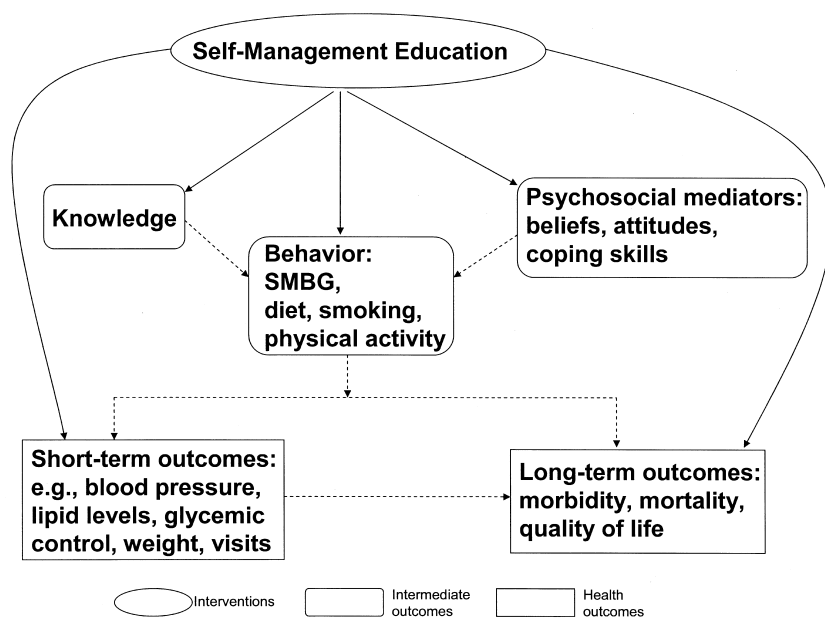
Traditional methods of healthcare delivery do not adequately address the needs of individual people or populations with diabetes. For example, in a survey of the care received by patients of primary care providers, people with diabetes were receiving only 64% to 74% of the services recommended by the ADA Provider Recognition Program.<sup>8</sup> A chart audit covering one year in a health maintenance organization (HMO) setting showed that, despite the ADA recommendation of two to four glycosylated hemoglobin (GHb) measure-



**Figure 5–1.** Analytic framework illustrating the relationships between disease and case management and short- and long-term health care, system, provider, and client outcomes. (BP = blood pressure, PA = physical activity, SMBG = self-monitoring blood glucose.) (Reprinted from Am J Prev Med, Vol. 22, No. 4S, Norris SL et al., The effectiveness of disease and case management for people with diabetes: a systematic review, p. 17, Copyright 2002, with permission from American Journal of Preventive Medicine.)

ments per year, values were documented for only 44% of people with diabetes and annual urine protein measurements were performed on only 48% of patients.<sup>9</sup>

Improving care for people with diabetes reduces healthcare costs. In a review of economic analyses of interventions for diabetes, eye care and pre-conception care were found to be cost-saving, and preventing neuropathy in type 1 diabetes and improving glycemic control for either type 1 or type 2 diabetes were found to be clearly cost-effective.<sup>10</sup> Using modeling techniques at an HMO, it was found that every percentage point increase in A1c (a test that measures a person's average blood glucose level over the past two to three months) above normal was associated with a significant increase in costs over the next three years.<sup>11</sup> Decreases in A1c result in cost savings: one study noted that improved glycemic control was associated with short-term decreases in the use of healthcare services, increased productivity, and enhanced quality of life,<sup>12</sup> and another found that achieving and sustaining glycemic control for one to two years was associated with cost savings among adults with diabetes.<sup>13</sup>



**Figure 5–2.** Analytic framework illustrating the relationships between self-management education and short- and long-term client outcomes. (SMBG = self-monitoring blood glucose.) (Reprinted from *Am J Prev Med*, Vol. 22, No. 4S, Norris SL et al., Increasing diabetes self-management education in community settings: a systematic review, p. 40, Copyright 2002, with permission from American Journal of Preventive Medicine.)

In the 1990s, innovative interventions for healthcare delivery emerged, which show promise for improving care, improving health outcomes, and reducing costs for individuals and populations with diabetes. Disease and case management are two such new interventions.

Our conceptual approach to the reviews of disease and case management interventions, as well as the relationships between the interventions and provider and patient outcomes, are shown in Figure 5–1. Disease management involves many factors in the health-care delivery system and among providers and patients, as illustrated in Figure 5–1. Case management can be implemented along with disease management, by itself, or with other interventions.

Disease and case management can affect patient knowledge<sup>14</sup> and such psychosocial factors as motivation,<sup>15</sup> social support,<sup>16</sup> and health beliefs,<sup>16,17</sup> which in turn predict how well a patient will care for him- or herself. Patient self-care behaviors (e.g., self-monitoring of blood glucose) and lifestyle directly affect blood pressure, lipid concentrations, glycemic control, renal function, lesions of the feet, and diabetic retinopathy,<sup>18–26</sup> which, in turn, affect long-term health, quality of life, and mortality.<sup>18,27–31</sup>

***Disease Management: Recommended (Strong Evidence of Effectiveness)***

These interventions use organized, proactive, multicomponent approaches to healthcare delivery for people with diabetes. Care is focused on, and integrated across, the spectrum of the disease and its complications, the prevention of comorbid conditions, and the relevant aspects of the delivery system, with the goal of improving both short- and long-term health or economic outcomes.

***Effectiveness***

- Disease management is effective in reducing GHb by approximately 0.5 percentage points.
- Disease management is also effective in improving provider monitoring of GHb by approximately 16 percentage points and lipid levels by approximately 24 percentage points.
- Disease management is also effective in improving provider screening for retinopathy by approximately 9 percentage points, foot lesions and peripheral neuropathy by approximately 27 percentage points each, and urine protein (proteinuria) by approximately 10 percentage points.

***Applicability***

- These findings should be applicable to adults with diabetes in managed care organizations and community clinics in the United States and Europe.

Disease management has played a prominent role in innovative systems of clinical care over the past two decades. The earliest application of a disease-focused intervention involved prescription drugs,<sup>32</sup> and the first use of the term *disease management* appears to have been in the late 1980s at the Mayo Clinic.<sup>33</sup> In the mid-1990s the term emerged in the general medical literature, and by 1999 approximately 200 companies offered disease management services.<sup>34</sup> The initial focus of disease management was cost control, but more recently, quality and economic efficiency have driven disease management interventions. These interventions are used in several clinical care areas, primarily for costly chronic diseases or conditions such as heart failure,<sup>35,36</sup> arthritis,<sup>37</sup> and depression.<sup>38,39</sup>

We define disease management<sup>40</sup> as an organized, proactive, multicomponent approach to healthcare delivery that involves all members of a population with a specific disease such as diabetes. The essential components of disease management are (1) identification and management of people with diabetes or a subset with certain risk factors for poor outcomes (e.g., cardiovascular disease risk factors), (2) guidelines or performance standards for care, (3) information systems for tracking and monitoring, and (4) measurement and management of outcomes. Disease management can be combined

with interventions that focus on the patient or population (e.g., DSME), the provider (e.g., reminders or continuing education), or the healthcare system or practice (e.g., practice redesign). For example, a small group of providers might initiate the following as a disease management program: People with diabetes are identified from billing records or provider and support staff recollection. Patients' names are placed in an electronic file (e.g., a spreadsheet, a relational database, or software specifically designed for this purpose). This database records A1c, the last visit, and the last retinal and foot exams. Once a month, a nurse or support staff member reviews the database and calls or mails reminders to patients who are in need of visits and screening. A team of providers, including a nurse whose role is to coordinate and monitor the care of people with diabetes, then delivers care that follows evidence-based diabetes care guidelines.

Our definition of disease management excludes many programs that may refer to themselves as *disease management*. This review and its recommendations apply only to programs that encompass the four components of disease management in our definition. We did not examine the effectiveness of individual components or the effectiveness of various other combinations of interventions.

The findings of our systematic review are based on 27 studies (in 28 reports) that evaluated the effectiveness of disease management in improving patient health and provider practices.<sup>41-68</sup> An additional eight studies were identified but did not meet our quality criteria and were excluded from the review.<sup>69-76</sup> The 27 studies provided evidence of effectiveness for several patient and provider outcomes. Glycated hemoglobin improved in 18 of 19 studies, with a median absolute decrease of 0.5 percentage points (interquartile range, 0.1 to 1.35). We found strong evidence of improvement in the percentage of providers who performed annual monitoring of GHb and retinopathy screening, and sufficient evidence of improvement in screening for foot lesions or peripheral neuropathy, lipid concentrations, and proteinuria. A small number of studies examined the effectiveness of disease management on other important patient outcomes, including weight and body mass index, blood pressure, and lipid concentrations. These studies reported inconsistent results, and therefore provided insufficient evidence to determine the effectiveness of the intervention on these outcomes.

The improvements in glycemic control as measured by GHb, as well as an increase in the percentage of providers who perform annual monitoring of GHb and retinopathy and other screening, show that disease management is effective in improving patient health and provider practices.

These findings should be applicable to adults with diabetes in managed care organizations and community clinics. No studies examined children with dia-

betes. Studies were conducted predominantly in urban centers in the United States and Europe.

Although type 1 diabetes patients were not examined exclusively in any study, these results should apply to adults with type 1 diabetes. Despite important differences between people with type 1 and type 2 diabetes, the goals of treatment and general management guidelines are identical. Thus, effective methods of population management are likely to be similar for adults with type 1 and type 2 diabetes. Disease management has been studied in minority and racially mixed populations, but it remains unclear how cultural characteristics might affect outcomes. One possible difference could be varying levels of access to health care. Gestational diabetes (which develops in 2% to 3% of all pregnant women and disappears with delivery<sup>1</sup>) was not specifically studied, but disease management interventions should also apply to affected individuals.

Studies generally involved the entire population of providers in a facility, although in some studies the researchers selected specific providers to participate or the providers volunteered. Researcher- or self-selected providers may have more of a commitment to change or have greater skills in systems change, the use of practice guidelines, or team approaches to care, thus limiting the applicability of these studies to other providers.

Studies were conducted in a variety of managed care organizations (including network or primary care-based models and staff or group model HMOs as well as community clinics). Other settings (academic centers, a hospital clinic, and the Indian Health Service)<sup>67</sup> were examined, but the data were insufficient to determine the effectiveness of disease management in those settings. Where community clinics and managed care delivery systems differ from other delivery systems, applicability to those other types of delivery systems could be limited. However, findings in HMOs may be applicable to other organized systems, such as the Indian Health Service.

The findings of our systematic review of economic evaluations are based on two studies. The first study, a cost analysis conducted in Scotland, reported the average cost for adult patients of an integrated care disease management intervention versus traditional hospital clinic care.<sup>49</sup> Integrated care patients were seen in a general practice every three or four months and in the hospital clinic annually. General practitioners and patients received consultation reminders, patient records were consistently updated, and practices received care guidelines. Traditional care patients were seen at the clinic every four months and received appointment reminders. Costs included those associated with general practice and clinic visits (staff, administrative, overhead, and supply costs). The annual average adjusted costs were \$143–\$185 for integrated care and \$101 for traditional care. After two years, no significant



difference was seen between the two groups for GHb, body mass index, creatinine, or blood pressure. The integrated care patients, however, had higher annual rates compared with the traditional care group for routine diabetes care visits (5.3 versus 4.8) and frequency of screening and monitoring of GHb (4.5 versus 1.3), blood pressure (4.2 versus 1.2), and visual acuity (2.6 versus 0.7). The applicability of these findings is limited to general practice and hospital clinic settings.

The second study was a cost–benefit analysis of preconception plus prenatal care versus prenatal care only for women with established diabetes.<sup>1</sup> Preconception care involves close interaction between the patient and an interdisciplinary healthcare team (primary care and specialist physicians, nurse educator, dietitian, and social worker), intensive evaluation, follow-up, testing, and monitoring to optimize glycemic control and reduce adverse maternal and infant outcomes. The analysis modeled the program’s costs and benefits, or savings, from reduced adverse maternal and neonatal outcomes. Program costs included personnel, laboratory and other tests, supplies, outreach, delivery, and time of the patient and a significant other. Costs for maternal and neonatal adverse outcomes were for hospital, physician, and subsequent neonatal care. Costs attributable to future lost productivity of the mother and child were not included. The preconception care intervention’s adjusted cost saving (net benefit) of \$2702 per enrollee was the difference between estimated prenatal care only and the preconception and prenatal care intervention costs (program costs plus maternal and neonatal adverse outcome costs). The savings resulted largely from preventing the most expensive adverse events—congenital anomalies. The incremental benefit–cost ratio of 1.86 was the adverse outcome cost savings of the preconception plus prenatal care intervention versus the prenatal only program divided by the difference in program costs. This ratio represents the savings for each additional dollar invested in the preconception and prenatal care program versus the prenatal care only program.

Although not evaluated in the literature, we also identified potential barriers to implementing disease management interventions among organizations, providers or support staff, and patients. Organizations may lack the leadership to support these interventions and the financial resources needed for implementation and maintenance, or they may lack practice guidelines and the necessary skills and resources to develop guidelines. (Several practice guidelines are publicly available, such as the guidelines published annually by the ADA.<sup>5</sup>) Providers practicing in the traditional mode of reactive care may find that the switch to proactive, organized management requires the redesign of much of their practice and approach to patient care, including appointment and follow-up scheduling; allocation of clinic time to review registries and

practice guidelines; delineation of the roles of support staff and providers; the delegation of care traditionally performed by physicians to other professionals, such as nurses; team organization; and the use of planned visits and patient reminders.<sup>77-79</sup> Providers may find disease management time-consuming, particularly initially, and they may be inexperienced or uncomfortable with information systems. Barriers to using practice guidelines, described elsewhere,<sup>80</sup> include lack of awareness of or familiarity with them, disagreement with the guidelines, lack of confidence that patient outcomes can be improved, inability to overcome the inertia of previous routines, and external barriers such as inconvenience and insufficient time. In addition, there may be little or no reimbursement for delivering patient reminders and other proactive care strategies. Identifying patients to participate in these interventions, also often difficult, can be accomplished through provider and staff memory, hospital discharge summaries, claims data,<sup>81,82</sup> visit encounter forms, laboratory test results, patient-initiated visits, or pharmacy activity. Patient barriers include difficulties in maintaining a healthy lifestyle and the complexity of diabetes self-management.<sup>83</sup>

In conclusion, the Task Force recommends disease management on the basis of strong evidence of effectiveness in reducing GHb and of increasing the percentage of patients screened annually for diabetic retinopathy. Sufficient evidence was also found for improving provider screening for foot lesions or peripheral neuropathy, lipid concentrations, and proteinuria. These findings should be applicable to adults with diabetes in managed care organizations and community clinics in the United States and Europe.

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***Case Management: Recommended (Strong Evidence of Effectiveness)***

Case management identifies people at risk for excessive use of healthcare resources, poor coordination of healthcare services, or poor health outcomes and addresses their needs through improved planning, coordination, and provision of care. Authority is assigned to one professional (the case manager) who is not the direct healthcare provider, but who oversees and is responsible for coordinating all of the patient's care. Case management can stand alone as a single-component intervention, can be combined with other clinical care interventions (e.g., practice guidelines or patient reminders), or can be part of a disease management intervention.

***Effectiveness***

- Case management is effective both when delivered in conjunction with disease management and when delivered with one or more educational, reminder, or support interventions.

- Glycated hemoglobin improved when case management was part of a disease management intervention (approximate decrease 0.5 percentage points) or alone (approximate decrease 0.4 percentage points).
- Case management is effective in improving provider monitoring of GHb by approximately 33 percentage points as part of a disease management intervention.

#### *Applicability*

- These findings should be applicable primarily to adults in managed care settings in community clinics in the United States.

Case management is an important intervention for people at high risk for adverse outcomes and excessive use of healthcare services.<sup>84</sup> It usually involves the assignment of authority to a professional (the case manager) who is not the provider of direct health care, but who oversees and is responsible for coordinating and implementing care. In interventions involving diabetes, the case manager is generally a non-physician, most commonly a nurse.

Case management was first used in nursing and social work as early as the 1850s,<sup>85</sup> and the terminology has evolved. The term *care management* is often used instead (the American Geriatrics Society prefers this term to others<sup>86</sup>). The effectiveness of case management has been examined in a number of diseases, conditions, and situations other than diabetes, including psychiatric disorders,<sup>87</sup> chronic heart failure,<sup>88</sup> geriatric care,<sup>89</sup> and care initiated at the time of hospital discharge.<sup>90,91</sup>

Case management in diabetes has five essential features:

- Identification of eligible people—those at high risk for excessive resource use, poor outcomes, or poor coordination of services. All people with diabetes might be targeted, but more commonly a subset with specific disease risk factors (e.g., coexisting cardiovascular disease or poor glycemic control) or high healthcare usage (e.g., as determined by visits or costs) is targeted.
- Comprehensive assessment of each individual's needs.
- Development of an individual care plan.
- Implementation of the care plan.
- Monitoring of outcomes. Monitoring of the individual patient or population may involve several outcomes, including process (e.g., client satisfaction, service usage), health, quality of life, or economic (e.g., cost, hospital admissions) outcomes.

Case management interventions are often incorporated into multicomponent interventions, making it difficult to assess the effectiveness of case management alone. Interventions that can be combined with case management include self-management education (DSME, reviewed in this chapter), home visits, telephone call outreach, telemedicine, and client reminders.

The findings of our systematic review are based on 15 studies (in 18 reports) that examined the effectiveness of diabetes case management.<sup>42,45,46,50,51,55,58,60-62,64,70,92-97</sup> Nine additional studies were identified but did not meet our quality criteria or did not report on relevant outcomes and were excluded from the review.<sup>72,98-105</sup> The 15 reviewed studies provided data on numerous provider and client outcomes. Improvement in GHb was similar when case management was delivered with disease management and when it was not. When delivered with disease management, the evidence of its effect on provider monitoring of GHb was sufficient to show its effectiveness. When delivered either alone or in combination with disease management, the evidence was insufficient to determine the effect of case management on lipid concentrations, weight or body mass index, and blood pressure, as studies were few, with inconsistent results. The quality of life improved in two studies.

These results show that case management, whether combined with disease management or with another educational, reminder, or support intervention, is effective in improving both monitoring of GHb levels and GHb levels themselves.

These findings should be applicable to adults in U.S. managed care settings. All but one study was performed in the United States. Settings were primarily managed care organizations, although an academic center, community clinics, a military clinic, and a veterans' hospital were also studied. In most studies, the entire eligible population of providers at a clinic or in a health-care organization was recruited to participate, except for three studies that used a subset of providers.

Study populations, mainly adults with type 2 diabetes, were predominantly mixed by sex and race. One study was of children with type 1 diabetes (mean age, 9.8 years). Demographic information, including age and type of diabetes, was not reported in many studies.

Case management was implemented along with disease management in many of the studies. Other studies included such additional interventions as DSME, telemedicine support, insulin-adjustment algorithms, group support, client reminders, and hospital discharge assessment and follow-up. It was therefore not possible to determine the isolated effect of case management in these studies.

We did not find any economic evaluations of case management.

Possible barriers to implementation are discussed above under Disease Management.

In conclusion, the Task Force recommends case management on the basis of strong evidence of effectiveness in improving glycemic control. When com-

combined with disease management, case management is also effective in improving provider monitoring of GHb. These findings are applicable primarily to adults in managed care settings in the United States.

### ***Diabetes Self-Management Education***

Diabetes self-management education (DSME), the process of teaching people to manage their diabetes,<sup>106</sup> has been considered an important part of the clinical management of diabetes since the 1930s.<sup>107</sup> The American Diabetes Association (ADA) recommends assessing self-management skills and knowledge of diabetes at least annually and providing or encouraging continuing education.<sup>108</sup> Diabetes self-management education is considered “the cornerstone of treatment for all people with diabetes” by the Task Force to Revise the National Standards for Diabetes Self-Management Education Programs,<sup>106</sup> a group representing national public health and diabetes-related organizations. This need is also recognized in objective 5–1 of *Healthy People 2010*:<sup>4</sup> to increase to 60% (from the 1998 baseline of 40%) the proportion of people with diabetes who receive formal diabetes education.

The goals of DSME are to achieve optimal metabolic control and quality of life and to prevent acute and chronic complications while keeping costs acceptable.<sup>109</sup> Unfortunately, 50% to 80% of people with diabetes have significant knowledge and skill deficits,<sup>110</sup> and mean glycated hemoglobin (GHb) levels are unacceptably high both in people with type 1<sup>111</sup> and those with type 2<sup>112</sup> diabetes. Furthermore, less than half of the people with type 2 diabetes achieve ideal glycemic control<sup>113</sup> (A1c < 7.0%).<sup>108</sup>

The abundant literature on diabetes education and its effectiveness includes several important reviews demonstrating the positive effects of DSME on a variety of outcomes, particularly at short-term follow-up.<sup>83,110,114–118</sup> These reviews, however, and most of the existing literature focus primarily on clinical settings.

Our conceptual approach to the reviews of diabetes self-management interventions is shown in Figure 5–2. We reviewed the effectiveness of DSME delivered outside of traditional clinical settings, in community centers, faith institutions, and other community gathering places; the home; the worksite; recreational camps; and schools. We did not examine evidence on the effectiveness of clinical care interventions for the individual patient; recommendations on clinical care may be obtained from the ADA,<sup>5</sup> and screening recommendations are available from the U.S. Preventive Services Task Force.<sup>6</sup> Our review focused on people who have diabetes and did not address primary prevention of diabetes. For prevention of type 2 diabetes, the best strategies are weight control and adequate physical activity among high-risk people, including those with impaired glucose tolerance.<sup>119</sup>

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***Diabetes Self-Management Education in Community Gathering Places:  
Recommended for Adults with Type 2 Diabetes (Sufficient Evidence of Effectiveness)***

Diabetes self-management education for people 18 years of age or older can be provided in such community gathering places as community centers, libraries, private facilities (e.g., cardiovascular risk reduction centers), and faith institutions. Although recommended for improving glycemic control, the interventions reviewed were rarely coordinated with the individual's clinical care provider, and the nature and extent of care in the clinical setting was unclear. These interventions should be coordinated with the individual's primary care provider and are not meant to replace education delivered in the clinical setting.

***Effectiveness***

- Diabetes self-management education in community gathering places is effective in decreasing GHb by approximately 2 percentage points.

***Applicability***

- These findings should be applicable to adults with type 2 diabetes, with a range of racial and ethnic backgrounds, in a variety of settings.
- Applicability may be limited, however, because study populations were self-selected, had high attrition rates, and had high baseline GHb levels.

We reviewed DSME interventions in which people aged 18 or older were educated in settings outside the home, clinic, school, or worksite because clinic settings may not be ideal for DSME, the home setting is conducive only to individual and family teaching, and the worksite is available only to people who work outside the home. Thus, DSME in community gathering places may reach people who would not normally receive this education. Church-based health education and screening programs are effective in helping African Americans,<sup>120</sup> particularly women 65 years of age and older, to adopt new behaviors.<sup>121</sup> Community interventions often offer the benefit of cultural relevance, possibly because the diverse learning styles of different cultures are better addressed in the community setting. The increased cultural relevance may increase acceptance of diabetes education.<sup>122</sup> Interventions in community gathering places also may be more convenient, especially for those in rural areas, and may thus promote attendance.

The findings of our systematic review are based on eight studies (in 12 reports) that evaluated the effectiveness of DSME in community gathering places.<sup>123–134</sup> Three additional studies were identified but did not meet our quality criteria or did not report on relevant outcomes and were excluded

from the review.<sup>135–137</sup> The reviewed studies evaluated changes in GHb levels (four studies); knowledge (one study); fasting blood glucose (four studies); physical activity (one study); dietary intake (one study); or changes in weight (six studies), blood pressure (two studies), and lipid concentrations (three studies). The improvements in glycemic control (pooled estimate [weighted average], a decrease of 1.9%, 95% CI: 1.4, 2.4; four studies) provided sufficient evidence of effectiveness to recommend DSME in community gathering places. Evidence, however, was insufficient to determine the effectiveness of this intervention in improving dietary intake, physical activity, weight, blood pressure, or lipid levels because of the small number of studies and inconsistent effects.

These results should be applicable to adults with type 2 diabetes, with a range of racial and ethnic backgrounds, in a variety of settings. Applicability may be limited, however, by the fact that those studied chose to be in the studies and had high attrition rates as well as high baseline GHb levels. The mean age of the study populations ranged from 43 to 71 years in the seven studies that reported age. Seven studies examined both male and female populations, and five studies reported racial and ethnic backgrounds: Native American (two studies) and Mexican American (three studies). The six studies that reported the type of diabetes all involved people with type 2 diabetes. Baseline mean GHb levels were high, with a mean of 12.3% (range, 11.7% to 15.8%). The population in six studies consisted of self-selected volunteers, with randomly selected populations in the other two. All eight studies were performed in the United States, three in rural areas.

The interventions were conducted in a variety of settings: faith-based institutions (two studies), community centers (five studies), and a Pritikin residential treatment center (one study). Interventions focused on a variety of issues: general diabetes education and self-care, diet, physical activity, and diet combined with physical activity. The interventions in three studies were coordinated with primary care providers, but the nature and extent of clinical care was unclear. Attrition rates varied from 0% to 79%; in four studies these rates exceeded 20%, and no study compared dropouts to completers.

A lack of quality control and accountability could negatively affect the quality of programs in community settings, although no studies in our review examined this issue.

We did not find any economic evaluations of DSME in community gathering places.

We identified several potential barriers to implementing these interventions. In community settings, it may be difficult to find people who should receive DSME training. Participants are generally self-selected, and more general re-

cruitment may be difficult. Another issue may be coordinating these interventions with the patient's primary care team.

In conclusion, the Task Force recommends DSME in community gathering places for adults with type 2 diabetes, on the basis of sufficient evidence that DSME is effective in improving glycemic control among people of varying ages and ethnic or racial backgrounds. Several precautions should, however, be noted. (1) Applicability may be limited because study populations were self-selected and had high attrition rates and high baseline GHb levels. (2) The studies rarely reported coordination with the clients' clinical care provider, and the nature and extent of care in the clinical setting was unclear. DSME for adults delivered in community gathering places should be coordinated with the individual's primary care provider, and should not be considered a replacement for education in the clinical setting until adequate coordination is established.

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***Diabetes Self-Management Education in the Home: Recommended for Children and Adolescents with Type 1 Diabetes (Sufficient Evidence of Effectiveness) Insufficient Evidence to Determine Effectiveness for People with Type 2 Diabetes***

The home can be a good setting for DSME training, allowing the educator to address issues that may be more difficult to deal with in clinical settings, such as cultural, family, and environmental factors affecting lifestyle, self-monitoring of blood glucose, and barriers to optimal self-care.

*Effectiveness*

- Diabetes self-management education in the home is effective in improving glycemic control among children and adolescents with type 1 diabetes, whether conducted through home visits or computer-assisted instruction.
- Evidence was insufficient to determine the effectiveness of DSME in the home for people of any age with type 2 diabetes.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

*Applicability*

- The recommendation should be applicable to children and adolescents with type 1 diabetes.

In most of these home-based interventions, educators come to the home of the person with diabetes to assess and address issues that may not be apparent or may be more difficult to manage in the clinical setting. These issues include cultural, family, and environmental factors affecting lifestyle (particularly diet and physical activity), problem solving, self-monitoring of blood glucose,



glycemic control, and the prevention and management of complications. Information and support can also be provided through computer-assisted instruction and electronic communication with healthcare professionals.

The findings of our systematic review are based on 10 randomized controlled trials that evaluated the effectiveness of DSME interventions in the home.<sup>97,138–146</sup> An additional eight studies were identified but either did not meet our quality criteria or did not report on relevant outcomes and were excluded from the review.<sup>103,147–153</sup> The reviewed studies examined knowledge, self-care skills, self-concept, use of healthcare services, birthweight and gestational age, quality of life, weight, foot appearance, blood glucose, and GHb levels.

Six studies examined GHb levels and were stratified by type of diabetes. Evidence of the effectiveness of DSME in the home on glycemic control was sufficient to recommend use of this approach for adolescents with type 1 diabetes (pooled estimate [weighted average], a decrease of 1.1%, 95% CI, 0.6, 1.6; four studies) but not for adults with type 2 diabetes (pooled estimate, a decrease of 0.5%, 95% CI, –0.1, 1.1; two studies). Evidence of the effectiveness of DSME in the home was insufficient to determine its effectiveness on other psychosocial, behavioral, or health outcomes for people with both type 1 and type 2 diabetes because of the small number of studies that examined these outcomes.

The recommendation should be applicable to children or adolescents with type 1 diabetes. Studies of young people with a mean age of 9 to 14 years were performed in the United States, Canada, and Australia; race or ethnicity was not reported in any of them. The recommendation, however, does not extend to people with type 2 diabetes because only two studies examined this population and their findings were inconsistent.

We identified other potential positive effects of DSME in the home. It could increase the involvement and support of the family and thereby improve lifestyle, knowledge level, and social support for people with diabetes. It could also lead to positive changes in diet and physical activity for family members, which could both help the person with diabetes maintain these new behaviors and prevent development of diabetes in relatives. People who have difficulty visiting a clinic may especially benefit from DSME in the home. We did not find any harms of this intervention.

The findings of our systematic review of economic evaluations of DSME in the home are based on one study.<sup>154</sup> This cost analysis study at the Montreal Children's Hospital in Canada reported the average cost of intensive home care, including insulin adjustment and DSME, for a group of children aged 2

to 17 years. Following diagnosis and hospitalization to stabilize their metabolic condition, home-care patients were discharged, whereas traditional-care patients remained hospitalized for insulin adjustment and DSME. Education content was similar in the two settings. The home-care intervention consisted of visits by a specially trained nurse who was also available by telephone and an extra post-discharge clinic visit. Costs measured included those for health system resources (hospital supplies, services, and non-physician staff time, and physician and counseling services) and parent out-of-pocket and time costs for 24 months. Costs not included were an identical family monthly government allowance for insulin and medical supplies, diabetes-related health services not provided by the hospital, and overhead and residents' and interns' services at the hospital. The average program costs for the home intervention (adjusted to the *Community Guide* reference case) were \$50 per child more than for traditional-care patients (a nonsignificant difference between groups). Mean GHb levels were 10% lower for the home-care patients at 24 and 36 months. The two groups differed little in the use of hospital and physician services during the 24 months. The findings in this study are applicable to hospital settings with post-discharge home-care support.

Several potential barriers to implementing this intervention should be noted. Identifying people who would benefit from DSME in the home may be difficult because they may rarely be seen in a clinic and thus would not be well known to the healthcare team. Similarly, in the clinic it may be difficult to identify those patients whose families and living situations present barriers to self-management.

In conclusion, the Task Force recommends DSME in the home on the basis of sufficient evidence of effectiveness in improving glycemic control among children and adolescents with type 1 diabetes. This recommendation should be applicable to all children or adolescents with type 1 diabetes. Evidence was insufficient, however, to determine the effectiveness of this intervention on glycemic control or other outcomes for people with type 2 diabetes because of the small number of studies that examined these outcomes.

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***Diabetes Self-Management Education in Summer Camps:  
Insufficient Evidence to Determine Effectiveness***

Diabetes self-management education in summer camps for young people with diabetes exposes children and adolescents with diabetes to intensive self-management education. Summer camp sessions usually last one or two

weeks. At camp, DSME can be readily integrated into daily routines, optimal compliance with educational and medical treatment can be achieved, food intake is controlled, medical expertise is usually readily available, and children can safely pursue physical activity.

#### *Effectiveness*

- Although 10 qualifying studies were identified, evidence was insufficient to determine the effectiveness of DSME in summer camps in improving health outcomes such as glycemic control because of the limited number of studies that measured this outcome.
- The studies also had limitations in study design and execution, as well as inconsistent results.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

Children with diabetes need to follow the same regimen of care year-round, and summer is often a challenging time for these children and their parents. With diverse outdoor activities and inconsistent routines, children may find it difficult to follow their schedule of daily monitoring, injections, and specific meal plans, or they may simply lose interest in doing so. To accommodate children and adolescents, the first residential summer camp for children with diabetes was established in 1925.<sup>155</sup> The camp's mission was to give these children a camping experience in a safe environment while enabling them to share their experiences and learn to be more personally responsible for the care of their disease.<sup>156</sup> Recreational camps are now frequently used for DSME of children and adolescents; in the United States over 90 camps serve more than 10,000 people.<sup>155</sup>

In the camp setting, the recreational, educational, social, and healthcare needs of children can be met in a safe, enjoyable, and productive environment. Diabetes self-management education can be readily integrated into daily routines, optimal compliance with educational and medical treatment can be achieved, food intake is controlled, medical expertise is usually readily available, and children can safely pursue physical activity.

The findings of our systematic review are based on 10 studies that evaluated the effectiveness of DSME interventions in recreational summer camps.<sup>157-166</sup> An additional five studies were identified but did not meet our quality criteria or did not report on relevant outcomes and were excluded from the review.<sup>167-171</sup>

Study participants, identified as having type 1 diabetes, ranged in age from 8 to 15 years and were both male and female. Three studies were conducted among an all-white population, and one study reported a racially mixed population. All interventions were performed in the United States.

Although seven studies did provide sufficient evidence of a positive effect on knowledge (part of the mission of these summer camps), with significant improvement in four studies, this evidence was insufficient to determine the effectiveness of recreational camps in improving glycemic control because of the limited number of studies that measured this outcome. Glycated hemoglobin levels improved in one of two studies where this outcome was measured, glycated albumin improved in a third study, and psychosocial mediators improved in three studies.

Because we could not establish the effectiveness of this intervention, we did not examine situations in which it would be applicable, information about economic efficiency, or possible barriers to implementation.

Other potential benefits of DSME in summer camps include the ability to combine DSME with recreational activities (e.g., give instruction about insulin adjustment just before physical activity), nutritious meals and snacks to help campers develop healthy eating habits, and peer support to help improve self-esteem and motivation. Through the relaxed, fun, non-clinical atmosphere of the camp setting, young people can come to associate DSME with a positive experience. We did not identify any harms of this intervention.

In conclusion, although sufficient evidence demonstrated a positive effect on knowledge for children and adolescents with type 1 diabetes, this improvement alone will not necessarily improve health. Because too few studies examined health outcomes such as glycemic control, the Task Force found insufficient evidence to determine the effectiveness of DSME in recreational camps.

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***Diabetes Self-Management Education at the Worksite:  
Insufficient Evidence to Determine Effectiveness***

Because workers with diabetes spend a significant portion of their time at work, DSME at the worksite can improve their access to health promotion efforts. In addition, education of supervisors, managers, and coworkers about diabetes can create a supportive environment and prepare them to respond appropriately to diabetes-related emergencies. It can also minimize discrimination against those with special needs created by diabetes.

***Effectiveness***

- The evidence was insufficient to determine the effectiveness of DSME at worksites in improving the health of workers with diabetes because it consisted of only one study, which had design limitations.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

Although the 1992 Americans with Disabilities Act prohibits employer discrimination against qualified people with disabilities and requires employers to provide reasonable accommodations, worksites still present many challenges to people with diabetes. These people are more likely to experience difficulty getting a job and staying employed than are people without diabetes,<sup>172,173</sup> and they experience more employer discrimination than do non-disabled workers.<sup>174,175</sup> Workers with diabetes often find it difficult to reconcile their daily diabetes-related routines with their job requirements, making the worksite a potentially important place for DSME. Bringing DSME to the worksite may make it easier for people with diabetes to attend and may provide valuable information for supervisors, managers, and coworkers. Supervisors and managers need to support healthy lifestyles; make allowances for meal and snack-time requirements, self-monitoring of blood glucose, and medical appointments; and promote understanding, tolerance, and support among coworkers.

The findings of our systematic review are based on one study that examined the effectiveness of DSME at the worksite.<sup>176</sup> Two other studies were identified but did not meet our quality criteria and were excluded from the review.<sup>177,178</sup> Although improvement was shown in GHb levels (a decrease of 1.4 percentage points), this single study did not provide strong enough evidence of effectiveness for the Task Force to determine whether or not DSME at the worksite is effective in improving the health of people with diabetes.

Because we could not establish the effectiveness of this intervention, we did not examine situations in which it would be applicable, information about economic efficiency, or possible barriers to implementation.

We identified other potential effects, although these have not been evaluated in the literature. Education of coworkers could increase tolerance for and understanding of diabetes and other chronic diseases and minimize disability-related discrimination. Both the employee with diabetes and the employer could benefit from the increased employee productivity resulting from improvements in the work environment. Potential negative effects include labeling of workers with diabetes and issues related to the confidentiality of health information. Coworkers who learn about diabetes may be uncomfortable or fearful about how to respond to diabetes-related emergencies.

In conclusion, the Task Force found insufficient evidence to determine the effectiveness of DSME at the worksite in improving the health of workers with diabetes, as only a single study, with limitations in its design, was identified. Evidence of the effectiveness of educating coworkers about diabetes is also insufficient, as no studies were identified.

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*Educating School Personnel about Diabetes: Insufficient Evidence to Determine Effectiveness*

Educating teachers and other school professionals about diabetes can create a supportive environment for a student's self-management of diabetes, can minimize the disruptions in educational routines attributable to diabetes, and can teach school personnel appropriate ways of responding to diabetes-related emergencies.

*Effectiveness*

- The evidence was insufficient to determine the effectiveness of educating school personnel about diabetes in improving the health of students with diabetes.
- Only one study, with design limitations, showed variable effects on knowledge and did not report on outcomes other than knowledge.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

To improve the health and well-being of students with diabetes, professionals in schools can be educated about the disease and the needs of their students. Most of the 125,000 children in the United States who have diabetes<sup>179</sup> attend school, and they need special accommodation at school to ensure their immediate safety, long-term physical and psychological well-being, and opportunities for optimal scholastic achievement. School personnel are required by law to provide health-related services to children who demonstrate an identified need.<sup>180</sup> Unfortunately, the level of teacher knowledge about diabetes, especially of life-threatening emergencies such as hypoglycemia, is inadequate and poses a serious threat to the safety and well-being of children who require assistance.<sup>181</sup> School personnel, particularly teachers, receive inadequate or no training to prepare them for dealing with children who have chronic health conditions.<sup>182-184</sup> When school personnel fail to respond to diabetes-related emergencies promptly and appropriately, the child with diabetes may suffer serious health consequences.<sup>185</sup>

The findings of our systematic review are based on one study, which evaluated the effectiveness of educating teachers and other school personnel about diabetes.<sup>181</sup> A second study was identified but did not meet our quality criteria and was excluded from the review.<sup>186</sup> The one qualifying study, with limitations in design and execution, showed varied effects on knowledge and did not report on any other outcomes. Therefore, the evidence was insufficient to determine whether or not educating school personnel about diabetes is effective in improving the health of students with diabetes.

Because we could not establish the effectiveness of this intervention, we did not examine situations in which it would be applicable, information about economic efficiency, or possible barriers to implementation.

We identified, but did not evaluate, other potential effects of this intervention. Education about diabetes could make teachers and students more tolerant not only of the needs of students with diabetes but also of the needs of students with other chronic conditions. Possible negative effects could include labeling or ostracism of the child with diabetes, issues of confidentiality, the opportunity cost of teacher education (using money for diabetes education that could be spent on preventing and treating more common health problems), and teacher anxiety associated with feeling personally responsible and potentially liable for a child's health and well-being.

In conclusion, the Task Force found insufficient evidence to determine the effectiveness of educating school personnel about diabetes in improving the health and well-being of students with diabetes. Only one study was included in the review: it had design limitations and only reported on changes in knowledge, where the effect was inconsistent.

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### **REDUCING THE BURDEN OF DIABETES THROUGH USE OF THESE RECOMMENDATIONS**

Diabetes affects children, adolescents, and adults of every racial and ethnic group everywhere in the United States. In addition to those who have the disease, the people with whom they live, learn, and work are also affected. Management of diabetes requires knowledge and a willingness to make lifestyle changes and special accommodations. The interventions recommended in this chapter can help people with diabetes manage their disease, which can result in fewer diabetes-related emergencies, overall better health, and, hopefully, greater enjoyment of life.

Healthcare systems can do a lot to help people with diabetes. Offering a combination of disease management and case management can both improve the health of people with diabetes and potentially reduce the costs of caring for diabetes and its related complications (e.g., cardiovascular disease, kidney disease, frequent use of health services in emergencies). A good starting point is to assess the current burden of diabetes, the level of care and education provided for clients with diabetes, and complication rates. This information can then be compared with the care guidelines and goals of treatment presented by organizations such as the American Diabetes Association (ADA) ([www.diabetes.org](http://www.diabetes.org)).

In selecting and implementing interventions, communities and healthcare systems should strive to develop a comprehensive strategy for people with diabetes, which includes improving blood pressure, lipid concentrations, and

glycemic control; decreasing complications and mortality; and improving the quality of life. Choosing effective interventions that are well matched to local culture, needs, and capabilities, and implementing those interventions well, are vital steps for improving outcomes among people with diabetes. In setting priorities for interventions to meet local objectives, recommendations and other evidence provided in the *Community Guide* should be considered along with such local information as resource availability; administrative structures; and the cultural, economic, social, and regulatory environments of organizations and practitioners. Information on applicability is provided to help decision makers determine if recommended interventions are appropriate in their particular settings. Although the Task Force generally does not use economic information to modify recommendations, this information can help in the decision-making process by identifying (1) resource requirements for interventions and (2) interventions that meet public health goals more efficiently than other available options.

If local goals and resources permit, the use of recommended interventions should be initiated or increased. Even though the Task Force found insufficient evidence to determine the effectiveness of DSME in summer camps, schools, and worksites, and in the home for adults with type 2 diabetes, the ADA ([www.diabetes.org](http://www.diabetes.org)) provides useful information about many aspects of living with the disease. Until sufficient evidence becomes available to determine the effectiveness of these approaches, readers are encouraged to become better informed about aspects of diabetes relevant to their situations. “Insufficient evidence to determine effectiveness” only means that too little evidence was available to determine whether or not the intervention is effective; it doesn’t mean that the intervention doesn’t work.

## CONCLUSION

This chapter summarizes Task Force conclusions and recommendations on interventions to reduce the burden of diabetes. For interventions in the healthcare system, the Task Force recommends both disease management and case management. To improve DSME, the Task Force recommends delivering DSME in community gathering places for adults with type 2 diabetes and in the home for adolescents with type 1 diabetes. Evidence was insufficient to determine the effectiveness of DSME interventions in the home for people with type 2 diabetes, in camps, or at the worksite. Evidence was also insufficient to determine the effectiveness of interventions to educate school personnel about diabetes. Details of these reviews have been published<sup>7,187–189</sup> and these articles, along with additional information about the reviews, are available at [www.thecommunityguide.org/diabetes](http://www.thecommunityguide.org/diabetes).



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This chapter was written by members of the systematic review development team: Susan L. Norris, MD, MPH, Division of Diabetes Translation (DDT), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC), Atlanta, Georgia; Phyllis J. Nichols, MPH, DDT/NCCDPHP/CDC, Atlanta; Carl J. Caspersen, PhD, MPH, DDT/NCCDPHP/CDC, Atlanta; Russell E. Glasgow, PhD, AMC Cancer Research Center, Denver, Colorado; Vilma G. Carande-Kulis, PhD, MS, Division of Prevention Research and Analytic Methods (DPRAM), Epidemiology Program Office (EPO), CDC, Atlanta; Susan Snyder, PhD, DPRAM/EPO/CDC, Atlanta; Michael M. Engelgau, MD, MSc, DDT/NCCDPHP/CDC, Atlanta; Leonard Jack, Jr., PhD, MSc, DDT/NCCDPHP/CDC, Atlanta; George Isham, MD, HealthPartners, Minneapolis, Minnesota and the Task Force on Community Preventive Services; Sanford Garfield, MD, Diabetes Program Branch, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Bethesda, Maryland; and David McCulloch, MD, Group Health Cooperative of Puget Sound, Seattle, Washington.

Consultants for the reviews were: Tanya Agurs-Collins, PhD, Howard University Cancer Center, Washington, DC; Ann Albright, PhD, RD, California Department of Health Services, Sacramento; Pam Allweiss, MD, University of Kentucky, Lexington, Kentucky; Elizabeth Barrett-Connor, MD, University of California, San Diego; Peter A. Briss, MD, MPH, DPRAM/EPO/CDC, Atlanta; Richard Eastman, MD, Cygnus, San Francisco, California; Luis Escobedo, MD, New Mexico Department of Health, Las Cruces; Wilfred Fujimoto, MD, University of Washington, Seattle; Richard Kahn, PhD, American Diabetes Association, Alexandria, Virginia; Robert Kaplan, PhD, University of California, San Diego; Shiriki Kumanyika, PhD, University of Pennsylvania, Philadelphia; David Marrero, PhD, Indiana University, Indianapolis; Marjorie Mau, MD, University of Hawai'i, Honolulu; Nicolaas P. Pronk, PhD, HealthPartners, Minneapolis, Minnesota; Laverne Reid, PhD, MPH, North Carolina Central University, Durham; Yvette Roubideaux, MD, MPH, University of Arizona, Tucson.

Articles included in the reviews were abstracted by: Semra Aytur, MPH; Inkyung Baik, PhD; Holly Murphy MD, MPH; Cora Roelofs, ScD; and Kelly Welch, BSc.

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