The Art and Science of Diabetes Care and Education

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ADCES
Association of
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CHAPTER 1

Diabetes Care and Education: Rich Past, Challenging Present, Promising Future

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Key Concepts

- Diabetes is a relentless global public health emergency requiring a multilevel system response.
- The financial impact of diabetes management threatens the viability of healthcare systems across the globe.
- Continued rapid technological development is associated with improved diabetes-related outcomes.
- Recognizing expanded roles and responsibilities in pre-diabetes, diabetes, and cardiometabolic diseases, the diabetes educator changed to the diabetes care and education specialists.
- Diabetes care and education specialists possess unique skill sets essential to the interdisciplinary care team in diabetes and cardiometabolic disease states.
- Education is necessary to but not sufficient for behavior change. Diabetes care and education specialists possess the knowledge, skills, and abilities to facilitate effective self-management in persons with diabetes and cardiometabolic conditions.
- The diabetes care and education specialists should be encouraged to practice to the full extent of his or her education (training) and expertise.
- Updated competencies assist the diabetes care and education specialists to grow and advance.
- Barriers to equal access to diabetes care and education must be addressed.

Diabetes Care and Education: Challenges and Opportunities

> *"Change will not come if we wait for some other person, or if we wait for some other time. We are the ones we've been waiting for. We are the change that we seek."*
>
> Barack Obama

Definitions of Terms

- **Epidemic:** A disease that affects a defined group of people in a specific geographic location simultaneously
- **Pandemic:** An extremely widespread or globally occurring disease that affects many populations simultaneously
- **Syndemic:** A combination of health or social conditions that interact to increase the disease burden to a community, further developing a public health concern

Pandemic. Amid the fear and devastation associated with the outbreak of COVID–19, the word *pandemic* has become part of everyday language throughout the world. The rapid spread of this novel virus is impacting the daily lives of the nearly 8 billion people living in today's world.

As of January 2020, the American Association of Diabetes Educators (AADE) is known as the Association of Diabetes Care & Education Specialists (ADCES). Either the organization's full name or the acronym will be used in this chapter, regardless of whether the text is referencing activities prior to 2020.

Healthcare and financial resources are focused, rightly so, on mitigating the impact of the deadliest infectious diseases in living history. And, during the crisis, life goes on. Non-communicable diseases (NCD) that have the power to alter the lives of individuals are not taking a break. In the United States, more than 171 people are diagnosed with and 28 people die from diabetes every hour.[1] Diabetes, at pandemic levels for years, is now considered “one of the fastest growing global health emergencies of the 21st century.”[2]

Certainly, there is a distinction, never more apparent than now, between communicable and non-communicable health emergencies. And, the importance of developing systems to rapidly respond to emerging health concerns cannot be minimized. At the same time, it is important not to lose sight of the needs of those with NCD. The negative impact exerted by diabetes mellitus on individuals and society is never-ending. The magnitude of impact will be most apparent in countries with fewest resources, but diabetes knows no boundaries. All segments of society in every corner of the world are affected by diabetes. Together, the quartet of diabetes, cardiovascular disease, cancer, and respiratory disease is responsible for 8 out of every 10 deaths attributable to NCD throughout the world.[3] Even within the wealthiest countries, including the United States, the effects of diabetes and prediabetes continue to exert significant effects on population health.[4] Without change, 15 million people are projected to die *prematurely* every year from NCD.[5] Fifteen million translates to more than 28 individuals every minute, of every day, 365 days of the year.

There are three primary forms of diabetes: type 1, type 2, and gestational diabetes. Each of these is addressed in detail in later chapters of this desk reference. Type 2 diabetes (T2DM) is the most common form, affecting up to 95% of all persons with the disease.[2,4] The development of type 2 diabetes is associated with genetics and epigenetics compounded by modifiable environmental risk factors including obesity, physical inactivity, and poor nutrition.[2,6] Although the onset of type 2 diabetes can be delayed or prevented by disrupting the association of 1 or more risk factors, continued worldwide growth makes it clear that type 2 diabetes has moved beyond pandemic levels into *syndemic* proportions.[3,7] Strong evidence shows the positive impact of healthy lifestyle behaviors on type 2 diabetes, and new data suggest that use of monoclonal antibodies may delay the onset of type 1 diabetes as well.[8,9] Once diagnosed, long-term complications of either type 1 or type 2 diabetes can be prevented or delayed with targeted diabetes management strategies.[4,7,10,11] These strategies include care, education, and ongoing support to facilitate healthy lifestyles aimed at achieving and maintaining target blood glucose levels.

Global Impact of Diabetes

In the *Atlas of Diabetes* published biennially, the International Diabetes Federation addresses the global impact of diabetes. According to 2019 data, the total estimated prevalence of diabetes in adults doubled during the past 20 years and currently affects 463 million worldwide.[2] Expected to rise another 25% over the next decade, the IDF is projecting a worldwide prevalence of diabetes over 700 million by 2045. This far surpasses previous projections. While growth is expected throughout the world, the largest increases are projected to occur in Africa (143%↑), the Middle East and North Africa (96%↑), South East Asia (74%↑), and South and Central America (55%↑). The largest increases are expected to occur as counties continue to develop and their economies improve.[2–4] Worldwide, type 2 diabetes continues to account for approximately 90% of all diabetes.[2] It is slightly more common in men than in women worldwide. In many countries, including the United States, T2D is far more common in nonwhite and older populations.[2,4,12] Type 2 diabetes is primarily a condition associated with aging. Whereas 9.3% of the overall adult population has diabetes, when the data are broken down according to age, nearly 20% of those over age 65 are shown to have diabetes.[2,4]

Across the United States, in addition to the estimated 34.2 million people with diabetes, another 88 million adults have prediabetes, bringing the total number of Americans with or at risk for diabetes to over 120 million.[4,13] In the United States, news is hopeful as examination of data collected between 2012 and 2017 reveals stability in prevalence rates as well as a reduction of incidence of diabetes in adults.[14] Even so, the impact of those who currently have or are at risk for diabetes combined with a continuing rise in worldwide prevalence rates are sobering and very serious. Assuming current projections are accurate, by 2050 as many as 1 in 3 adults throughout the world will have diabetes.[2,15,16] China, India, and the United States continue to lead the world in cases of diabetes, a situation that is not likely to change in the foreseeable future.[2]

Because diabetes affects all segments of society, the impact of this disease is far reaching. In 2010, an estimated 4 million deaths were attributed to diabetes worldwide, with the proportionate number of deaths from diabetes in middle-aged women sometimes reaching nearly 25%.[17] By 2017, the annual death rate attributable to diabetes had exceeded 4 million worldwide.[2] In the United States, diabetes is ranked as the seventh leading cause of death, and it is generally believed that estimates of mortality due to diabetes are greatly underestimated because the cause of death in persons with diabetes is often ascribed to other conditions.[3] Global targets to reduce premature death from non-communicable diseases 30% by 2030 have been established.[5] Despite unprecedented rapid advances in technology, healthcare systems in most countries are unprepared to deal with the consequences associated with a pandemic of this magnitude.[18] Public health initiatives promoting an understanding of the multifactorial nature of diabetes and its complications combined with targeted approaches to identify and treat diabetes and prediabetes appear to be helping to reduce the socioeconomic burden of this devastating disease. In the United States, for example, the National Diabetes Prevention Program (NDPP) is already demonstrating success.[13]

Incidence versus Prevalence

Health statistics often are expressed in terms of incidence and prevalence. The distinction between the two measurements is important when interpreting the data.

Incidence measures the risk of the target population developing the disease or condition being tracked over a specific time period. *Prevalence* measures the portion of the target population that has the disease or condition being tracked.

Incidence is calculated by taking the number of new cases of a disease or condition within a specific time frame—usually a year—and dividing by the size of the population.

Prevalence is calculated by dividing the number of individuals with the disease or condition at a particular point in time by the number of individuals examined.

There are differences in the incidence and prevalence of the primary types of diabetes. Many people are confused by the terms incidence and prevalence. The common definitions can be found in the sidebar, but there is an easy way to understand the difference. Think about prevalence as referring to those who are known to have the condition and incidence as those individuals who are newly diagnosed. Representing approximately 5% of all individuals with diabetes, the incidence of type 1 diabetes continues to rise. In other words, increasingly larger numbers of people are diagnosed with TID every year. The reasons for this persistent increase are unclear. While type 1 diabetes can be diagnosed at any point in the lifespan, it occurs most commonly in childhood and youth. Globally, 1,110,100 children and youth under age 20 years have type 1 diabetes, and more than 128,900 children develop type 1 diabetes annually.[2] In the United States, about 193,000 children and youth under age 20 years have type 1 diabetes with just over 18,000 new cases diagnosed each year.[4] Non-Hispanic whites in this age group have a relatively high incidence of type 1 diabetes compared with African-American, Hispanic, and Asian youth.[19,20] Data from the Search for Diabetes in Youth Study demonstrated an annual relative increase in incidence of 1.8% in the decade between 2002 and 20012.[21,22] Of note, these increases were seen in early school-age and mid- to late adolescent years, more often in boys, and in all racial/ethnic backgrounds except for Native Americans and Asian/Pacific Islanders.

Even though type 2 diabetes typically develops over many years and is more common in adults, type 2 is becoming much more common in children.[2,4] In the United States the incidence of type 2 diabetes in youth aged 10 to 19 years is increasing at an alarming 4.8% annually.[23] The increases are most pronounced in children of Native American and non-Hispanic Black ancestry, particularly among those who are overweight or obese. Ongoing reports from the SEARCH for Diabetes in Youth Study Group suggest that youth with type 2 diabetes have difficulty transitioning to adult care providers, experience higher levels of diabetes distress and depression, and demonstrate significant evidence of diabetes-related complications by the age of 21 years.[23]

Financial Impact of Diabetes

According to the most recent reports, the economic impact of diabetes continues to grow exponentially. In 2017, diabetes costs reached a level of $327 billion.[24] These costs rise to the level of $404 billion when prediabetes is added into the equation.[25] If analyzed on a state-by-state basis, the overall economic toll exerted by diabetes has been reported to be as high as $465 billion, with considerably higher indirect costs.[27] The cost of caring for diabetes far exceeds the cost of medical care in those without diabetes.[2,24] Several years ago, the cost of caring for diabetes in the United States was expected to be 20% of the gross domestic product (GDP) by 2016.[27] Currently, those with diabetes are responsible for 25% of the healthcare spending in the United States. Of that, 1 in every 7 healthcare dollars is used to pay for costs specifically linked to diabetes.[24] These costs include substantial direct medical expenses for inpatient care, outpatient care, emergency care, medications, and durable medical equipment, as well as indirect costs of absenteeism, reduced productivity at work, and lost productivity due to disability or premature death. Individuals with diabetes are more likely to be absent from work (absenteeism) and, while at work, suffer from fatigue or have reduced concentration; additionally, they may not be able to perform at a normal level (presenteeism). About 61% of all diabetes-related costs are attributed to the population over age 65 years.[24] Every day until 2030, 10,000 baby boomers will turn 65.[28] In 2009, Huang and colleagues estimated that 14.6 million people with diabetes would be Medicare eligible by 2034.[29] A more recent estimate of actual Medicare beneficiaries shows a diabetes prevalence rate of 31.6%, which translates to roughly 24.5 million people.[30] The price tag for medications to treat diabetes and diabetes-related complications accounts for about 30% of the direct costs of diabetes. Costs for antihyperglycemic medications have been steadily rising since 2001.[31] Taking inflation into account, the cost of all antihyperglycemic medications rose 45% between 2012 and 2017, but the cost of insulin during that time period rose 110%.[26] While the financial toll of diabetes will continue to adversely affect the ability of developed countries to finance their national healthcare systems, it will also have a considerable negative impact on the economic progress being made in developing countries.[2]

At the individual level, great disparities exist in the economic resources available to persons with diabetes in the United States. Prior to enactment of the Affordable Care Act (ACA), the number of uninsured in the United States was at 46.5 million. By 2016, that number dropped nearly 50% to 26.7 million. In 2017, the number of uninsured individuals in the United States began to rise. There are currently nearly 30 million uninsured in the country.[32] Medicare and Medicaid can be considered safety nets for older adults and those who meet or exceed the poverty threshold, but the working poor remain uninsured and continue to struggle. High deductibles that accompany insurance policies have an impact on a family's net income. When personal disposable income is limited, self-care practices can be significantly impacted

Diabetes Care and Education: A Brief History

Those familiar with Elliott P. Joslin's work will recall his passion for diabetes education and for involving individuals in their own care. As early as 1914, nurses were integral to Joslin's diabetes education model, serving as "diabetes wandering nurses," inpatient diabetes care specialists, and later as diabetes nurse educators.[33,34] In the 1950s and 1960s, diabetes teaching units were established at Deaconess Hospital in Boston and registered dietitians and "diabetes nurses" provided comprehensive diabetes education programs. The intended outcome of these programs was diabetes self-management for persons with diabetes and their families. Important and progressive, this level of diabetes care and education was uncommon. But around that same time in the mid-20th century, Donnell Etzwiler examined primary care practice patterns and the diabetes knowledge base of nurses and dietitians. In a 1967 paper, he concluded that diabetes teaching done in hospitals was provided by poorly prepared providers and that follow-up was rare.[35] Etzwiler, a prominent pediatric endocrinologist who was also passionate about the need for ongoing diabetes education and support, founded the International Diabetes Center (IDC) in Minneapolis in 1967.[37] Diabetes practices, clinics, and centers modeled after Joslin and the IDC soon appeared across the country, and diabetes education emerged as a specialty attracting primarily registered nurses and dietitians.[37,38] And, in 1974, a passionate multidisciplinary group of diabetes educators founded the Association of Diabetes Care and Education Specialists to serve the needs of this new and growing specialty.

Often occurring during hospitalization resulting from a diagnosis of diabetes, diabetes education in those early days might have been organized around the triad of diet, exercise, and medication management. In the 1980s home blood glucose monitoring became widely available and replaced urine glucose testing as the standard of care. "Control" of diabetes was the goal of care, and glycated hemoglobin testing became the gold standard for assessment. Debates about the use and frequency of self-monitoring of blood glucose (SMBG) were common. When federal regulations led to reduced hospital lengths of stay in the mid-1980s, out-patient diabetes education became more available. Insulin pump therapy (CSII) entered the field as a realistic alternative to multiple daily injections (MDI). Also in the 1980s, study sites for the proposed Diabetes Control and Complications Trial (DCCT) were selected and that (now epic) longitudinal study was initiated. In 1983, national standards and review criteria for diabetes education were developed and promulgated.[39] Using the new national standards, 39 diabetes education programs were awarded ADA recognition in 1986, and the first specialty certification exam for diabetes educators was offered that same year.[40–42]

Throughout the 1990s, diabetes care and education was marked by rapid scientific advancements. Human insulin was introduced to the market as the decade began, and insulin analogs entered the market shortly thereafter. Blood glucose monitoring and insulin pump technologies advanced rapidly. The Federal Drug Administration approved additional oral medications for the treatment of type 2 diabetes. Within the specialty, the term "diabetic diet" became obsolete as nutritional guidelines encompassed more successful strategies for healthy eating with diabetes. Results from the DCCT demonstrated the unequivocal value of targeting near-normal glucose levels in type 1 diabetes. The diagnostic cut-point for type 2 diabetes was lowered and the terminology characterizing diabetes changed to reflect pathophysiologic differences between the major variants of the disease. CSII or MDI combined with carbohydrate counting and frequent monitoring became the norm for management in T1D. The prevalence of overweight and obesity in children and adults was on the rise and type 2 diabetes began to appear in youth. As the evidence base grew and specialists were gaining more knowledge about diabetes management, the prevalence of diabetes was growing at an alarming rate of ~4.4% per year.[14] Greater numbers of diabetes educators were needed to serve a rapidly expanding population of people with diabetes. During this decade, the process and outcomes of diabetes education began to be increasingly person-centered.[43] And, in diabetes education, a paradigm shift was taking place.[44] Terminology began to reflect the change as educators moved from compliance to adherence to empowerment models. Reimbursement models were also shifting, and group sessions became increasingly more common in diabetes education.

It seemed that diabetes was on everyone's mind at the turn of the century. The first decade of the new millennium provided evidence supporting glycemic control for type 2 diabetes, and research linked healthy lifestyles with the delay or prevention of type 2 diabetes.[7–8,45,46] Incidence rates of diabetes, overweight, and obesity in the United States continued to surge. New classes of diabetes medications were added to the treatment arsenal. Incretin mimetics, DPP-4 inhibitors, long-acting insulin analogs, and an amylin analog were among the medications introduced to the market. Blood glucose monitoring, now ubiquitous to diabetes self-management, was faster and more reliable. Results were easy to download, analyze, and use during clinic appointments. Continuous glucose monitoring entered the market as a clinic-based option for complex care management. Terms like cultural competence, health literacy, diabetes distress, psychological insulin resistance, and empowerment became increasingly more common in the literature. The Chronic Care Model and the AADE7 Self-Care Behaviors® were adopted as organizing frameworks for diabetes education as the focus shifted toward active engagement and person-centeredness.[47,48] Evidence defining the value of diabetes education was published[27,49] but legislation requiring reimbursement for diabetes education services could not be realized. As the Association of Diabetes Care and Education Specialists (ADCES) identified the need for an advanced management credential, and the Board-Certified Advanced Diabetes Management® (BC-ADM®) was introduced to address the increasing complexities of diabetes education and management,[50–51] new provider categories such as community health workers emerged. Routinely reviewed and revised national standards for diabetes self-management education and support continued to reflect the evolving healthcare landscape. In 2009, the ADCES began offering program accreditation services. As of this writing, recognition through the American Diabetes Association or accreditation through the ADCES continue to serve as quality indicators for diabetes education programs.

If the first decade of the 21st century seemed like a whirlwind, the second decade has been nothing short of mind-boggling. At about the same time the world began to recover from a great recession, baby-boomers entered Medicare rosters at the rate of 10,000 new members per day. The twin epidemics of diabetes and obesity were still growing at an alarming pace. SGLT inhibitors, new combinations of diabetes medications, and new formations of insulins entered the market. New models of healthcare delivery systems such as Patient-Centered Medical Homes and Accountable Care Organizations were introduced. Reimbursement models focused on outcomes are the new norm. Duncan and colleagues published additional data about the value of diabetes education.[52] An ADCES-commissioned workforce analysis of diabetes educators appeared at about the same time as threats of an impending nursing shortage resurfaced. It became clear that the number of persons with and at risk for diabetes far exceeded the number and availability of existing diabetes educators. Programmatic costs and lack of reimbursement for services continued to plague diabetes education programs. And technology marched on. Real-time continuous glucose monitoring became an integral part of diabetes care for many persons with diabetes, especially those using insulin pump therapy. Telehealth, digital on-line communities, digital and mobile technologies, all grew and impacted diabetes education, care, and support in unprecedented ways. Research about locations of and providers for diabetes education is now common in the literature.[53–55] Individuals with diabetes can locate information about self-care and connect with like-minded others using any digital technology with access to the Internet. Community health workers, patient care navigators, health coaches, and care managers are now available and often used in, with, and by healthcare entities. And, along with sensitivity to the language used in health care, a focus on interprofessional care that includes the individual in shared decision-making models emerged. The "words matter" movement is gaining momentum as increasingly greater numbers of healthcare providers are learning how to use person-centered language in all encounters.

Diabetes Education: Profession or Specialty?

Diabetes education has been an important part of diabetes management since the early days of Elliott Joslin. Over the last half century, countless individuals devoted their professional careers to diabetes education. These early diabetes educators, mostly nurses and dietitians, are the recognized authorities in this field of expertise. They were trailblazers who understood that diabetes education involved more than distributing pamphlets. Many were involved in building the evidence base that supports current practice. Within today's diabetes community, clinicians know that structured diabetes self-management education and support (DSMES) results in better self-management knowledge and improvements in fasting blood glucose, A1C, lipid, and blood pressure levels in individuals across the lifespan, and that diabetes education with follow-up support delivered by diabetes educators also results in improved satisfaction and reductions in diabetes-related distress in persons with diabetes.[53,56,57] DSMES can lower A1C values by as much as 2.3%, and culturally appropriate diabetes education improves knowledge, healthy lifestyles, and A1C levels in ethnic minority groups.[58] There is no question that diabetes education is beneficial; arguably, it is critical to the success of the person with diabetes. Some leaders in the field have referred to diabetes education as a specialty, and others call it a profession. Which is it? Is diabetes education a profession or a specialty?

That very interesting question often causes considerable consternation and requires a little unpacking. What is a "profession"? Loosely defined, a profession can be any type of work, but many take a narrower approach and differentiate a "profession" from an occupation, trade, or industry. From an historical perspective, the first professions were law, medicine, and divinity (the Church.[59–61] Some say these three professions have been present from the start of time. Others identify periods in time that define social context and point to Ancient Greece, the Roman Empire, the time of Enlightenment, the Reformation, or even the Industrial Revolution. Most likely, the primary professions arose during the Middle Ages and were refined intermittently throughout more recent history.[60,62] A good understanding of the history of and criteria defining professions comes from the work of Abraham Flexner. Flexner was an academic in the early 20th century. Subsequent to his seminal report on the state of medical education in the United States and Canada, he presented a paper that detailed the characteristics of professions in 1917. Reprinted in 2001, his criteria of a profession have endured over time.[61] Flexner listed six essential characteristics of a profession. Consistent with more contemporary literature, these classic criteria can be distilled down to the following five characteristics.[60,62] First, professions must provide a service essential to human welfare. Next, each profession is responsible to develop, use, communicate, and grow a specialized, scientific body of knowledge. Third, admission to the profession requires formal education gained through institutions of higher learning at the conclusion of which members demonstrate competency through licensure and credentialing. Fourth, members practice autonomously. They develop and follow clear standards of practice for which they are legally and publicly accountable. Finally, members are bound to and guided by a strict code of ethics. This common set of values is typified by honesty, trustworthiness, and altruism. Over time, many more professions were added to list including, to name a few, accounting, architecture, journalism, nursing, nutrition and dietetics, social work, pharmacy, and the professorate. Experts continue to disagree about which disciplines have achieved professional status.

To answer the question of whether diabetes education is a profession, each criterion should be examined separately. The essential nature of diabetes education is debatable. Evidence clearly confirms the value of diabetes education and support when it is delivered by a qualified provider. Still, diabetes education is a recommended, not required strategy for those with newly diagnosed diabetes. And, many providers, both licensed and unlicensed, deliver what they believe to be diabetes education. Diabetes education is both an art and a science. The body of knowledge needed for diabetes education comes from related disciplines such as medicine, pharmacology, physiology, nutrition, exercise science, and more recently from health education, nursing, and other healthcare professions. Some diabetes educators conduct and disseminate research, particularly research specific to the process and outcomes of diabetes education. The body of knowledge specific to diabetes education is absolutely growing. Programs designed to prepare diabetes educators are uncommon. Rarer still are programs at the college or university level, but all programs of study in the primary clinical professions include course and clinical content specific to diabetes. In some disciplines, academic programs may offer diabetes as a specialty or provide fellowship opportunities. Licensure to practice as a diabetes educator is not required in most states, provinces, or countries, but certification does require licensure in a specified healthcare discipline.[63,64] Because certification is a voluntary activity, those who deliver diabetes education may or may not be certified. With respect to autonomy, there is considerable variability. Diabetes education practice is mostly collaborative, often directed, but seldom independent. Most importantly, diabetes educators are first educated in an established discipline, eg, medicine, nursing, nutritional science, pharmacy. Thus, each provider is responsible for knowing and following the state rules and regulations for their primary profession and is accountable to his or her state of residence for doing so. The standards of practice and codes of ethics to which most clinicians are accountable derive from their primary profession and state statutes. And, the Certification Board for Diabetes Care and Education requires that all who take the CDCES® exam agree to follow the cannon of ethics promulgated by the CBDCE Board.[65] See Table 1.1.

If diabetes education does not completely meet the Flexner benchmarks of a profession, it certainly qualifies as a clinical specialty. It is one that thousands of clinicians choose to practice and from which millions of individuals with diabetes benefit. Although 93% of today's diabetes educators have backgrounds in nursing, dietetics, or pharmacy, clinicians from a wide range of healthcare occupations, including social work, dentistry, podiatry, and exercise physiology choose to specialize in diabetes education.[66] Diabetes education has a long history punctuated by amazing successes. It is not only challenging and rewarding, it is genuinely interprofessional and characterized by a team approach that keeps the person with diabetes at the center of the care circle.

TABLE 1.1 Evaluating the Status of Diabetes Education as a Profession

	Yes	*No*	*Maybe*
Does diabetes education provide a service **essential** to human welfare?			X
Have diabetes education providers **independently** developed, used, communicated, and expanded a specialized, scientific body of knowledge?			X
Is an **academic degree** in the specialty required?		X	
Is licensure and/or **credentialing required** for practice?		X*	
Do diabetes educators have full control (**autonomy**) over their practice?		X	
Are members bound to and guided by a strict **code of ethics**?			X
Do members share a **common set of values** typified by honesty, trustworthiness, and altruism?	X		

*Licensure is required in Kentucky and Indiana.

From Diabetes Education to Diabetes Care and Education:

Many diabetes educators have been on the leading edge for decades, embracing new technologies and advocating for a clinical practice environment focused on person-centered care and support. In the 1980s and 1990s, educators had pivotal roles in the Diabetes Control and Complications Trials.[67–69] More than 20 years ago, Feste, Anderson, Funnell, and colleagues[44,70–72] first began publishing work about person-centered approaches using empowerment. And, in 2003, Mulcahy and colleagues identified behavior change as the unique outcome of diabetes education and introduced the world to AADE7®.[73] Now classic research demonstrated that while knowledge is an essential prerequisite for self-care, knowledge alone is not enough to promote behavior change.[44,74,75] In response to changes in diabetes management and a growing body of evidence, best practices for diabetes education evolved to focus on strategies that promote and support effective person-centered self-management.[72,76,77] From the beginning, person-centered empowerment approaches to DSMES have been successful because they are based on principles of self-determination and support for autonomy.[72,77]

In 2015, the Association of Diabetes Care and Education Specialists (ADCES), the Academy of Nutrition and Dietetics (AND), and the American Diabetes Association (ADA) published a joint position statement within which they collaboratively defined diabetes self-management education (DSME) as "the process of facilitating the knowledge, skill, and ability necessary for diabetes self-care" and diabetes self-management support as "the support required for implementing and sustaining the coping skills and behavior needed to self-manage on an ongoing basis.[75] The goal of diabetes self-management education and support (DSMES) encompasses improved quality of life, self-care behaviors leading to improvements in a wide variety of clinical attributes, and decreased healthcare costs.[46,76,78–80] To achieve this using a person-centered approach, diabetes educators need sophisticated skill sets built on a solid core of foundational knowledge. Self-management is continuous and often difficult, but effective diabetes education and support can lead to positive outcomes to satisfy all involved in the process.

The term "diabetes education," which served the specialty well for decades, no longer fully represents the educator's breadth of responsibilities. DSMES is not only effective for people with diabetes; it is instrumental in preventing type 2 diabetes in those with prediabetes.[49,52] In recent years, diabetes educators have been increasingly more knowledgeable about prediabetes, diabetes prevention programs, obesity management, and risk reduction for cardiometabolic disease. Whether through independent practice, collaborative direct care, or the referral process, a majority of diabetes educators are more involved in influencing practice.[66] So, in keeping with practice patterns, DSMES has most recently been defined as "the interactive, collaborative, ongoing process involving the person with diabetes or prediabetes and/or the caregivers and the specialist(s)."[81] This is an important change because despite an expanding evidence base that supports the legitimacy of its impact, diabetes education remains chronically underutilized.[56,66]

This begs the question: if it is so effective, why is diabetes education underutilized? A part of the answer can be linked with the Internet, where health information sources abound. People know that information is available at the touch of a button. A recent literature search revealed over 6,000 publications for the combined terms "health information" and "internet." The body of knowledge on this topic has been growing for years. The fifth iteration of the Health Information National Trends Survey (HINTS), supported by the National Cancer Institute, concluded in 2018. Data from HINTS can be generalized to identify all health information seeking trends on the Internet. Those who seek digital health information tend to engage with providers at a higher level, experience better quality of life, and be more satisfied with healthcare decision-making.[82] Information technology is so much a part of contemporary health care that use of the Internet to seek health information was identified as a goal for Healthy People 2020.* Not all, but increasingly more people are coming to healthcare appointments armed with information they downloaded from an Internet source. Still, digital disparities exist. The gaps in access to online technologies are consistent with actual (in-person) healthcare access issues. Individuals who are older, poorer, non-white, less well-educated, rural, and sicker are less likely to access on-line sources.[83,84] Other researchers suggest that the Internet is neither universally trusted nor used and conclude that healthcare professionals should not assume that everyone is comfortable with or ready for Internet use.[85]

Easy access to health information does not fully explain low attendance at diabetes education classes or appointments. In the UK, Canada, and the United States, low attendance rates have long been a concern.[86] In recent years, investigators have begun to seek explanations once again. Winkley and colleagues found that those at greatest risk for diabetes complications were not the ones attending classes.[87] Instead, attendees were more likely to be women, individuals who did not smoke, and those who had lower A1C levels at diagnosis. Horrigan and colleagues[88] conducted a systematic review of literature and concluded that there were two main categories of people who declined the opportunity to attend diabetes education classes: those who could not attend for medical, timing, or financial issues and those who, for many reasons, saw no personal benefit from attendance. Other researchers found similar themes. Length of course, competing health issues, individual experiences and opinions, and personal priorities topped the list of reasons for non-attendance. Similar findings for non-attendance were identified subsequent to the systematic review.[86,89–91] Various strategies to improve attendance are suggested, including individualized sessions and systems-based support of programs. All agree that further study is needed.

Giving consideration to the problems associated with this rapidly changing diabetes and healthcare landscape and armed with the results of a detailed environmental scan, the ADCES Board of Directors established Project Vision to address current and future needs of the diabetes educator. The definition of the specialty and the expanding role of the educator are of foremost concern.[92] The pillars associated with Project Vision are outlined in the blue sidebar.

ADCES Project Vision Pillars

Drive Integration: Understanding that our value is in offering care that is holistic and seamless, it's critical that we integrate the clinical and self-management aspects of care.

Include Related Conditions: Diabetes isn't isolated, and neither are diabetes care and education specialists. We will demonstrate our expertise in the full range of cardiometabolic conditions: diabetes, obesity, hypertension, and cardiac disorders.

Focus on Behavioral Health: Supporting the emotional well-being of the whole person with diabetes must be a foundational element of the care we provide.

Leverage Technology: Diabetes care and education specialists will be technology experts and data interpreters, trainers, and consultants driving care.

Promote Person-Centered Care: We will continue to advocate so that every individual with diabetes and cardiometabolic conditions has access to a diabetes care and education specialist.

Achieve Quadruple Aim: We strive to offer care that positively impacts quality and cost and enhances the experience for both the person with diabetes and the provider.

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*As of this writing, Healthy People 2030 goals have not been finalized, but it is reasonable to expect to see goals for Health Information Technology.

From Diabetes Educator to Diabetes Care and Education Specialist

Diabetes educators have been defined as healthcare professionals who focus on helping people with and at risk for diabetes and related conditions achieve behavior-change goals which, in turn, lead to better clinical outcomes and improved health status. More than 20,000 healthcare providers from various professional disciplines, primarily nursing, dietetics, and pharmacy, were certified in the diabetes specialty in 2019.[93,94] Two mechanisms for certification in the specialty currently exist in the United States: the Certified Diabetes Care and Education Specialist® (CDCES®) credential awarded by the Certification Board for Diabetes Care and Education (CBDCE) and the Board Certified-Advanced Diabetes Management® (BC-ADM®) credential awarded by the ADCES. Criteria for certification, established by certifying bodies, typically include an educational background in health care, considerable experience in the specialty, and a comprehensive knowledge base. Other countries often have their own standards, processes, and names for the credentialed diabetes educator.

As noted previously, diabetes education involves more than information sharing. Diabetes educators use in-depth knowledge and skills in the biological and social sciences, communication, counseling, and education to provide self-management education and ongoing support to those affected by diabetes.[28,41] The title Diabetes Educator and its evolving definition served the specialty well for nearly 50 years. In 2019, the ADCES Board of Directors took a bold move and changed the title from Diabetes Educator to Diabetes Care and Education Specialist (DCES).[95] The name of the organization was changed to the Association of Diabetes Care and Education Specialists (ADCES) soon afterwards. As a result of these changes, the NCBDE changed its name to the Certification Board for Diabetes Care and Education (CBDCE) and the credential awarded to the Certified Diabetes Care and Education Specialist (CDCES).

Changing the title was neither taken lightly by the ADCES Board of Directors nor was it a quick process. It was a data-based, purposeful decision undertaken to reposition the educator as a critical resource within the healthcare team. Before taking this step, data from multiple sources were considered. For example, National Practice Surveys help to provide an understanding of the educator's role in the healthcare system. Eight biennial surveys have been undertaken by ADCES to date. Previous surveys demonstrated relatively stable demographics and practice changes consistent with the time frame.[94,96] While the most recent published data showed slight change in demographics, the results revealed shifting practice patterns, suggesting that the diabetes educator's role is expanding.[66] Depending on the setting and the educator's professional background and credentials, responsibilities might include DSMES, medical nutrition therapy, clinical management, disease management, counseling, and/or health professional education and research.[66,94] Diabetes care and education specialists practice in inpatient, outpatient, community, home care, academic, and other settings. They are involved in, among other things, direct care, program management, education of other healthcare professionals, research, social reform, and advocacy. And, as valued collaborators, they are becoming increasingly more involved with insulin initiation and titration, medication, device, and technology management.[66] Armed with this and other environmental scanning data, the ADCES Board outlined a vision that would allow for a diabetes educator to practice to the highest capacity of his or her license and to thrive in a dynamically changing environment. In December 2019, ADCES Board President Karen Kemmis stated that the role of the diabetes care and education specialist was envisioned as someone who could serve as an integrator for clinical management, education, prevention, and support. After formulating a comprehensive vision, the Board commissioned an external firm to gather additional data. At the conclusion of the process, the Board realized that the title "diabetes educator" adequately conveyed neither the educator's role within the integrated care team nor the breadth of the services they provided. An in-depth process to rename the specialty was undertaken, an outcome of which was the change in title. Various titles, including the current one, were tested among a broad base of stakeholders. The title Diabetes Care and Education Specialist was preferred by a majority. In December 2019, Kemmis noted that the title change moves the diabetes educator from a "knowledgeable and supportive advocate and coach who provides patient-centered education to people with diabetes" to "an expert who, as an integral member of the care team, provides collaborative, comprehensive and person-centered care and education to people with diabetes."

Diabetes Educator versus Diabetes Care and Education Specialist

Diabetes Educator

A knowledgeable and supportive advocate and coach who provides patient-centered education to people with diabetes

Diabetes Care and Education Specialist

An expert who, as an integral member of the care team, provides collaborative, comprehensive, and person-centered care and education to people with diabetes

Documents Supporting Practice

As the specialty evolved, so too did the documents supporting practice.[97–100] The earliest set of standards appeared in 1992. They were developed, in part, to accompany the National Standards for Diabetes Education and to assist educators to prepare for certification in the specialty. Definitions of diabetes education and the diabetes educator appeared in these initial guidelines. The role at that time was specifically limited to broad-based, comprehensive, and (ideally) interdisciplinary education. The 10 standards of practice (SOP) ranged from assessment through evaluation and included professional accountability and an ethical basis for practice.[97] Revised in 1999, the definitions of diabetes education and the diabetes educator broadened, and the six standards of educational practice were separated from the four standards of professional practice. The scope of practice continued to address the multidimensionality and multidisciplinary nature of the diabetes educator.[98] In the third version, the definition of DSME was broadened further.[99] The process now incorporated the AADE7 Self-Care Behaviors® and included group education and prevention. The six educational practice standards were rearranged, and the standards of professional practice, now called the standards of professional performance (SOPP), were expanded to include goals of care, professional performance appraisal, collaboration, and research. At about the same time, the ADCES began developing guidelines for the practice of diabetes self-management education (Guidelines) and competencies for diabetes care and education specialists (Competencies).[78,79] Initially intended to serve as companion documents to the Standards of Practice, the Guidelines incorporated much of the information from the SOP/SOPP and thus grew into the primary practice resource for people with diabetes, non–diabetes specialist providers, and other stakeholders.[78] In 2010, the SOP/SOPP were updated to reflect the new guidelines. Content of the SOP/SOPP were substantively unchanged, but the standards of professional performance were moved to an appendix.[100]

The Scope and Standards of Practice, Standards of Practice, and Standards of Professional Performance provided a framework for practice and guideline for excellence in diabetes education for more than 2 decades.[97–100] Importantly, scope of practice for diabetes education was always linked to state and/or national rules and regulations for the individual's primary profession. An intent of the original competencies and guidelines was to acknowledge the value of diabetes education providers across a broad continuum, from the community health worker to the advanced-level diabetes care and education provider. In the first version, the ADCES workgroup defined 5 levels of practice identifying a wide spectrum of practice ranging from the community health worker to the expert practitioner of diabetes education and/or management.[78] Revisions in 2013 and 2016 addressed the important contributions of all care providers, including the nontraditional and/or non-licensed healthcare worker and created a distinct category for the diabetes paraprofessional. Practice levels were condensed and competencies for each level of provider were developed and subsequently refined.[79,101]

Competencies for Practice

The first competencies for diabetes educators were published in 2009, and those for diabetes paraprofessionals were added several years later.[101,106] Competencies are intended to provide a road map for the development of the knowledge, skills, and abilities required for practice across the continuum of diabetes care.[79] The original competencies were organized according to provider level, using the Dreyfus Model and Bloom's revised taxonomy as organizing frameworks.[105,106] According to the Dreyfus model, experience is gained over time, and the individual moves from the level of advanced beginner to competent and then to proficient professional. With increasingly more time in the specialty, one moves through the levels of proficiency and gains an increasingly wider body of diabetes specialty knowledge and skills through achievement of competencies.[102,103] The knowledge base needed to provide quality diabetes education is multifaceted, so the competencies are structured into broad categories called domains. There were 292 original competencies, organized according to domain and level of practice, for the diabetes educator in the original document. In the most recent version, there were 126 competencies, sorted into two levels across five domains for the paraprofessional and 220 competencies for three levels of diabetes educator over the same five domains.[101]

Given the new vision and anticipated title change, in 2019 the ADCES Board of Directors recognized the need to revisit the Guidelines and Competencies. An inclusive, interprofessional, and geographically diverse workgroup was empaneled and charged with the task of reviewing and revising the existing practice documents. Work toward revision began in 2019 with a comprehensive review of the current practice documents followed by a review of literature specific to competencies in diabetes education as well as in related disciplines. Consistent with previous versions, the group decided to use the Dreyfus framework to organize competencies and Bloom's revised taxonomy to identify appropriate verbs for measuring the cognitive domain.[102,103] The group also decided to follow a Delphi technique to ensure rigor in the approach.[104] Using the Delphi technique provided a mechanism for the group to survey a larger group of experts in the field to ensure consensus with competency statements. A modified approach allowed for initial development of domains and competencies by the workgroup followed by input from selected experts. The draft document identifies six domains, crafted using this consensus methodology. The proposed domains compared with the existing domains can be found in Table 1.2. Updated competencies for the DCES and for others engaged in diabetes education and support will be published elsewhere when they become available.

Whether or not he or she is certified in the specialty, the diabetes care and education specialist will have achieved an advanced body of core knowledge and skills common to diabetes care and education above that which is required by their primary profession. The revised competency statements are intended to assist the DCES to build a foundation of knowledge and to grow as needed by his or her individual practice. Based on self-evaluation, each DCES will identify competencies appropriate for his or her practice, assess current knowledge in those areas, and seek educational opportunities where needed.

TABLE 1.2 Former and Proposed Domains for Diabetes Care and Education Specialists

	2016	*2020*	*Rationale for Change*
Domain 1:	Pathophysiology, Epidemiology, and Clinical Practice of Prediabetes and Diabetes	Clinical Management & Integration	Previously, this domain addressed the foundational knowledge of diabetes, including diabetes pathophysiology, epidemiology, and clinical guidelines. The updated Domain 1 focuses on clinical practice that integrates foundational knowledge.
Domain 2:	Culturally Competent, Supportive Care Across the Lifespan	Communication & Advocacy	Previously this domain encompassed competencies needed to provide culturally competent, supportive care across the lifespan. The updated Domain 2 focuses on communication competencies essential to optimize quality of care.
Domain 3:	Teaching and Learning Skills	Person-Centered Care & Education Across the Lifespan	Previously, this domain focused on aspects of teaching and learning and behavior change using aspects noted in the AADE7®. The updated Domain 3 identifies competencies necessary to partner with individuals to deliver care and education conducive to behavior change and improved quality of life for self-management of diabetes and cardiometabolic conditions across the lifespan.
Domain 4:	Self-Management Education	Research & Quality Improvement	Previously, this domain identified the competencies required to provide effective DSME while the updated version identifies research and QI competencies essential to guide research and quality improvement activities.
Domain 5:	Program and Business Management	Systems-Based Practice	Previously, the competencies in this domain enabled the educator to create a climate supporting successful self-management of diabetes. In the updated version of Domain 5, the focus is on application of business principles, population health management, and systems practice to positively impact outcomes of systems, providers, persons, and populations.
Domain 6:	N/A	Professional Practice	Domain 6 was added to address competencies related to lifelong learning and professionalism.

Source: Association of Diabetes Care & Education Specialists, *Competency Domains for Diabetes Care & Education Specialists* (Chicago: ADCES, 2020 (in review)).

Inclusivity: Others Engaged in Diabetes Care and Education

Recognizing that many individuals do not interface with a credentialed diabetes care and education specialist, ADCES has long held the position that all healthcare providers should have sufficient diabetes knowledge to provide safe clinical care for people with diabetes. Healthcare providers with a strong foundation in diabetes knowledge are more likely to choose to partner with diabetes care and education specialists and possibly even choose a diabetes specialty career path. With 122 million Americans already with or at risk for diabetes, clinicians, non-clinician providers, and peer supporters are all indispensable in the delivery of DSMES. Recognizing the importance of nonlicensed and/or supportive personnel, several years ago ADCES created a separate category of provider called the diabetes paraprofessional. Competencies for the paraprofessional were developed and embedded into ADCES practice documents. The practice levels for the paraprofessional illustrated the important role of the wide variety of non-licensed health workers in the work associated with diabetes education and support. Moreover, physicians, nurses, dietitians, pharmacists, and other healthcare providers, such as a master certified health education specialist (MCHES), who may routinely connect with individuals who have diabetes, but who do not specialize in diabetes, previously were captured as Level I educators.[105,106] These point-of-care healthcare professionals have, at a minimum, completed the educational requirements for a specific health profession's degree. They are licensed and/or registered to practice in their primary professional discipline and/or are members of a professional registry. Many have the basic background knowledge of diabetes inherent to academic training in health professions but have yet to develop a deep, broad-based diabetes specialty practice knowledge base. People with diabetes commonly interface with these providers in hospitals, clinics, schools, home care, and pharmacy settings. It is essential for them to have sufficient knowledge to provide safe care and accurate information to the individual with diabetes. As such, a role exists for competencies specific to others engaged in diabetes care and education.

Barriers and Facilitators to Access

Indisputable evidence supports the need for and benefits of well-managed diabetes.[8,10–11,57,107] Ideally, all people with diabetes are referred to a qualified diabetes care and education specialist, but only an estimated 25% or fewer people receive formal diabetes education at diagnosis. Although this is a grim statistic, the parameters of education have changed. Individuals with diabetes no longer need to wait for clinic appointments to "receive" diabetes education. Many take a proactive role in seeking out diabetes self-management information. What was once accomplished only in face to face appointments can now be achieved using digital technologies, including distance learning, videoconferencing, mobile health applications, technology enhanced DSMES, and self-paced learning modules.[108–111] With over 120 million Americans with or at risk for diabetes, access to diabetes care and education is essential. Based on the amount of published literature, clinical interest in prediabetes, diabetes and its related conditions is at an all-time high. The relationship between diabetes and other cardiometabolic conditions is clear.[112–115] CDC-recognized diabetes prevention programs are widely available and there is continued national emphasis management of diabetes.[4,94,116] The time seems to be ideal for diabetes care and education specialists and programs to thrive. And yet, barriers to diabetes care and education nevertheless exist.

Well-known barriers to DSMES access align with healthcare inequities. Age, race/ethnicity, socioeconomic status, educational preparation, language, and geographic location are all connected with access … or lack thereof. Some of the more common access barriers to DSME were identified a decade ago in a national study of individuals with diabetes (who were primarily white, well educated, and insured), diabetes educators, and physicians.[117] The results of this still-relevant study showed that DSME is highly regarded among those who have participated in it, but less so among those who have not. Individuals with diabetes and physicians alike want easier access to quality diabetes education. Because most individuals value their doctor's opinions, it was not surprising that primary care physicians were found to be essential to the referral process. Some physicians reported struggles with the referral process, and others reported having limited access to local educators. Most participating physicians reported wanting their patients to have more self-management support, but some disagreed with the diabetes care recommendations provided by the educator.

Geographic barriers still exist. Practice settings for diabetes care and education specialists vary widely. The majority of diabetes educator practices are in urban/suburban areas and in the hospital outpatient/clinic settings.[66,96,118] In 2014, Zrebiec reported that just over 20% of CDCESs practice in the Great Lakes states.[116] The so-called diabetes belt that covers most of the southeast, now extends upward into the eastern Great Lakes area, but the states with the highest prevalence of diabetes are Mississippi, West Virginia, and Alabama, states that are mostly rural, suggesting continuing lack of access to the DCES.[4]

Demographic barriers continue to exist. Elders living in long-term care (LTC) settings represent a particularly vulnerable group. Neither the frail elder with diabetes in LTC nor his or her caregivers commonly use the services or expertise of diabetes educators.[119] On the other end of the age spectrum, type 1 and type 2 diabetes both occur in children. Because children spend most of their day in the school setting, they need access to appropriate resources in schools. Fewer than half of all schools currently meet national guidelines for having 1 nurse for every 750 students.[120] And, while some efforts are being made to improve diabetes competency of school nurses, school personnel in general are poorly prepared to support the needs of the child with diabetes.[71,120] Significant cultural barriers still exist. The largest-growing populations of individuals with diabetes are in non-white cultures, races, and ethnicities. Too few programs are tailored to meet the needs of these individuals.[109] There is room for improvement for diabetes educators to increase the diversity within their workforce to better reflect the populations that they serve.[66,96] And, clinical inertia continues to exist.[121]

An identified barrier in the public health space was inadequate reimbursement for DSMES.[122] While third-party payers may recognize the value of and be willing to underwrite or reimburse for quality DSMES, a challenge is to define quality measures associated with DSMES services. Willingness to support DSMES services will be a critical factor as healthcare delivery models continue to be redesigned. Programs demonstrating quality in delivery and outcomes are expected to be highly sought after. One way to ensure quality is by achieving and maintaining accreditation or recognition status. The ADCES and the ADA offer accreditation or recognition status to programs meeting established criteria. The Centers for Disease Control and Prevention (CDC) has established accreditation standards for diabetes prevention programs, and The Joint Commission (formerly JCAHO) provides accreditation for inpatient diabetes management. Morgan et al identified difficulty earning program recognition status in the public health arena. This latter point identifies an opportunity for the enterprising diabetes care and education specialist to partner with public health programs, articulating the depth and breadth of diabetes care and education specialist services available, assisting in the development of programs, and/or serving as an ongoing consultant.[122]

The diabetes care and education specialist can respond to these and other barriers by capitalizing on the rapidly expanding technology environment. For example, as work toward creating interoperable electronic health records (EHR) continues, the diabetes care and education specialist can develop community partnerships that link EHR systems to enable automated referrals. Because there are multiple modes of learning, there are individuals who may always prefer face-to-face programs, but even those who have reported valuing traditional DSMES sources and settings also like media-based education strategies. This finding is as true today as it was in 2009.[86,88,91] The DCES can also combine technology with more familiar strategies like promoting worksite and faith-based DSMES programs, developing statewide coalitions to address referrals, and identifying champion providers who understand the value of DSMES and are willing to refer.[122] The question is: to what will they refer? How will the evolving healthcare system and seemingly limitless advances in technology change DSMES? Diabetes information is everywhere. Perhaps nothing, as much as this, illustrates the need to move beyond diabetes education and toward diabetes care and education services. It will be up to the diabetes care and education specialist to find ways to add value and purpose to individual and shared visits, and to also find novel ways to incorporate person-centered technologies and resources into programs and services.

Evolving Healthcare Systems in the United States

Few observers would dispute the fact that the healthcare system in the United States remains fragmented and dysfunctional. Healthcare outcomes continue to be disappointing despite the allocation of nearly 18% of GDP to healthcare spending.[4,123] Although chronic diseases have supplanted acute illnesses as the primary reasons for seeking health care in the United States, the healthcare system continues to primarily use an acute care delivery model. Creative mechanisms are being explored in the hope of mitigating the impact of rising healthcare costs, and the fee-for-service model common to US health care is slowly being overtaken by alternative designs, including the patient-centered medical home (PCMH), integrated delivery networks (IDNs), and the accountable care organization (ACO).

mHealth and the 21st Century Cures Act

The *21st Century Cures Act* (*Cures Act*) was created to help streamline the process for drug and device approval and was signed into law in 2016 (Pub.L. 114 - 255, 2016), authorizing over $500 million in funding to be used by the FDA to carry out provisions in the *Act,* through the year 2025.[124,125] Title III of the *Cures Act* contains 10 subtitles; Subtitle F addresses Medical Device Innovations. Fast-tracking medical product development allows for faster, more efficient introduction of innovations and advances to those who need them. A certified full-text version of the *21st Century Cures Act* may be accessed through the Congress.gov Web site: https://www.congress.gov/bill/114th-congress/house-bill/34. The *Cures Act* discusses the use of various measures, user experience information, and observational data from standard clinical use (ie, "real-world evidence") to facilitate more rapid drug and device approval. However, "real-world evidence" is broadly defined and can be perceived as subjective.[126] Those opposed to the *Cures Act* have expressed concern that it would allow drugs and devices to be approved based on weak evidence, possibly bringing dangerous or ineffective devices to market.[126,127]

The US Food & Drug Administration (FDA) monitors reports of issues with medical devices, alerting the public and health professionals when indicated, to ensure proper use of devices and the health and safety of those using the devices.[124,125] The FDA asks device users and healthcare providers to report adverse events associated with the use of any diabetes management device to MedWatch, the FDA Safety Information and Adverse Event Reporting Program, by following the voluntary reporting guidelines described on their Web site (https://www.fda.gov/safety/medwatch-fda-safety-information-and-adverse-event-reporting-program/reporting-serious-problems-fda). Recently, the FDA warned persons with diabetes and healthcare providers against the use of devices for diabetes management not authorized for sale in the United States: FDA Safety Communication.[128]

The unprecedented spread of mobile technologies along with advancements in their innovative application to address health priorities has evolved into a field known as mHealth.[129] The World Health Organization defines mHealth as medical and public health practice supported by mobile devices (eg, mobile phones, monitoring devices, and other wireless devices). mHealth refers to the concept of mobile self-care such as smartphone and tablet apps that enable consumers to capture their own health data, with or without a clinician's assistance or interpretation. The most common application of mHealth is the use of mobile devices to educate consumers about preventive healthcare services. Consumers are increasingly using mHealth technology to meet their health information needs, for health self-management, and as a communication tool with their providers. It's important to evaluate the usability of mHealth technologies before they are made available to users.[129,130] Recent studies indicate a need for in-depth evaluation of user experiences with mHealth technologies.[129,131]

A variety of frameworks may be applied for evaluating mHealth technology, such as the *Health-IT Usability Evaluation Model (Health-ITUEM),* the *Think Aloud Usability Test,* the *Usability Problem Taxonomy (UPT),* the *Framework Analysis (FA) method,* and the *System Usability Scale (SUS)* described in several studies.[130–132] Furthermore, to help standardize the quality of mHealth evidence reporting, the mHealth evidence reporting and assessment checklist (mERA) has been developed.[129] The US FDA's Center for Devices and Radiological Health (CDRH) initiated the Fostering Medical Innovation: Software Precertification Pilot Program for the assessment of companies that perform software design and testing for digital health devices.[133] This program aims to balance the benefits and risks of digital health products and to speed the review process of marketing applications for software products. This voluntary pilot program is a transparent and open approach to provide continuous notice and solicitation of public input, by means of an open public docket, throughout the program development. Comments may be posted on the public docket available on the Regulations.gov Web site: https://www.regulations.gov/comment?D=FDA-2017-N-4301-0001.

Relevant to the Diabetes Care and Education Specialist

In this era of rapid technological growth and increasing an individual's interest in self-management of diabetes, the diabetes care and education specialist must be informed regarding usability ratings of new technologies and be apprised of any safety issues reported by the FDA. Meta-analyses and systematic reviews published in high-impact, peer-reviewed journals offer excellent recommendations. The *Journal of Medical Internet Research* is a peer-reviewed open-access source established in 1999 which covers eHealth and "healthcare in the Internet age," touting an impressive journal impact factor of 4.95 in 2018.

The diabetes care and education specialist must also consider real-time updates being shared on social media as a potential source of information. #OpenAPS is a worldwide movement with nearly 4000 followers who share an interest in making artificial pancreas (APS) technology available more quickly to persons with type 1 diabetes.[134] Using OpenAPS (open source) software and diabetes management devices (eg, continuous glucose monitors and insulin pumps), some followers of #OpenAPS have constructed their own artificial pancreas systems subsequently reporting lowered hemoglobin A1C levels and improved sleep quality.[134] This example illustrates valuable insight, data, and experiences that can help everyone (device manufacturers, healthcare providers, and individual users) to build better tools to better manage life with diabetes. Many persons with diabetes are interested in directly improving diabetes technology by donating their data and sharing their experiences of living with do-it-yourself closed-loop systems.[134] Since these hybrid systems are not sold as medical devices, they are not subject to FDA regulation, creating some ethical concerns as to their safety.[134] The diabetes care and education specialist must be aware that the FDA has not evaluated the safety and effectiveness of unauthorized diabetes management devices or systems that combine devices in unintended ways, and that these devices or systems may give incorrect results and introduce unknown risks. Diabetes care and education specialists may be interested in subscribing to FDA Medical Device Safety Communication email alerts, which include clinical recommendations for self-management, by visiting the FDA Web site at https://www.fda.gov/medical-devices/safety-communications/2019-safety-communications.

Diabetes care and education specialists are in an ideal position to engage individuals in research and product development opportunities. Furthermore, they are ideally suited to encourage medical device adverse event reporting to MedWatch and advise patients to use only diabetes management devices the FDA has authorized for sale in the United States and to use these devices according to manufacturer instructions. To inquire about the FDA regulatory status of any product, the manufacturer can be contacted directly, or the FDA Division of Consumer Education can be reached at DICE@FDA.HHS.GOV, or by calling 800-638-2041 or 301-796-7100.[133] In an era of rapidly emerging technologies, the DCES may witness in clinical practice that which has not yet been published or reported by the FDA. Social media, even with its challenges and limitations, can offer noteworthy, real-time information of interest to all stakeholders in diabetes care and education.[136]

Diabetes Care and Education Specialists and the Affordable Care Act*

Although individuals with diabetes benefit from DSMES, many persons with diabetes have not had the advantage of receiving diabetes management guidance from a DCES. As healthcare delivery and payment structures in the United States evolve, diabetes care and education specialists are wondering what patterns will change and how comprehensive changes to the healthcare system will affect persons with diabetes. Health insurance coverage constitutes an important first step in obtaining access to care, managing disease, preventing complications, and reducing the likelihood of developing related conditions.[138] Moreover, lack of health insurance coverage results in increased out of pocket costs and delays in treatment, thereby substantially impacting the US economy. The Patient Protection and Affordable Care Act[139] plays an important role in the evolving healthcare system.

The Patient Protection and Affordable Care Act, also known as the Affordable Care Act (ACA), is sometimes called "Obamacare" because is became public law during the Obama administration (Pub. L. No. 111-148, 2010). The law contains 2 parts: the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act. The official and consolidated (unofficial) versions of these Acts are available in PDF or HTML formats on the HealthCare.gov Web site. This ACA has 3 primary goals:[139]

- Make affordable health insurance available to more people.
- Expand Medicaid programs to cover adults with an income below 138% of the federal poverty level.
- Support innovative medical care delivery methods designed to lower the costs of health care.

When the ACA passed, it represented an opportunity to decrease the toll of diabetes in the United States.[140] Many of the ACA provisions did not go into effect until 2014. During the 116th Congress (2019-2020), over 1700 bills which directly pertain to the ACA have been introduced or resolved. Numerous bills have been introduced to repeal the ACA (eg, H.R. 2536). Additional bills have been introduced to protect Americans with preexisting conditions (eg, H.R. 986), for lowering prescription drug costs (eg, H.R. 987), restoring access to medication (S.1089), and for protecting individuals from higher insurance premiums (eg, H.R. 2447).

The ACA expanded insurance coverage, consumer protections, and access to primary care services. The law contains several provisions of specific interest to persons with diabetes, policymakers, and healthcare providers, including the DCES. These provisions directly address gaps in diabetes prevention, screening, and care, creating a comprehensive approach toward improved treatment.[139] The Catalyst to Better Diabetes Care Act of 2009, built

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*The following information on the Affordable Care Act is current as of January 19, 2020. Ongoing healthcare reform news updates are summarized and may be viewed at Health Markets Web site at: (https://www.healthmarkets.com/resources/health-insurance/trumpcare-news-updates/).[137]

into the ACA, authorized the CDC to enhance surveillance of diabetes and to develop national quality standards for a national diabetes report card.[139] The *Diabetes Report Card* contains current information on the status of diabetes, gestational diabetes, prediabetes, preventive care practices, risk factors, quality of care, outcomes, and progress made toward meeting national goals.[4]

Diabetes-related provisions include wellness and prevention programs, Medicaid Health Homes for those with chronic conditions, the Medicaid Incentives to Prevent Chronic Disease Program, and the Medicare Independence at Home Demonstration Program.[139] The complete ACA contains 10 titles (or divisions), each addressing a particular aspect of reform. The next section contains a description of the 10 titles and offers a consolidated summary of the contents of the ACA, highlighting specific implications for the diabetes care and education specialist. The titles are summarized in Table 1.3. This brief summary is not intended to represent the entirety of this law.

Title I: Quality, Affordable Health Care for All Americans

Through shared responsibility, the ACA promises to transform healthcare coverage, access, and quality for all Americans as it is introduced incrementally, by 2020.[139] Persons with diabetes may particularly benefit from this important federal legislation, given the significant reforms for preventive services included in the act.[139] Borne out of the ACA is the National Diabetes Prevention Program, representing a partnership of public and private organizations working to reduce the growing problem of prediabetes and type 2 diabetes.[116,139]

This section discusses improvements in healthcare coverage for all Americans, including preventive health services. If the plan offers dependent coverage for an unmarried child, this coverage is available until the child turns 26. Wellness and prevention programs which include weight management, physical fitness, nutrition, heart disease, and diabetes prevention are specified. Subtitle B of this section elaborates actions to preserve and expand insurance coverage for those with preexisting conditions. Subtitle C describes quality health insurance coverage for all Americans, prohibiting preexisting condition exclusions or other discrimination based on health status. Covered essential health benefits include ambulatory services, emergency services, hospitalization, prescription drugs, lab services, preventive/wellness services with chronic disease management, as well as oral and vision care for children. Levels of coverage for Bronze (lowest level of coverage), Silver, Gold, and Platinum levels (highest level of coverage) are described. Flexibility in operation and enforcement of exchanges is permitted to vary by state, and states may establish alternative programs. Subpart B of this section describes procedures for determining eligibility. Title I addresses individual and small-business tax credits, individual and employer responsibilities, and a variety of miscellaneous provisions.

TABLE 1.3 The Affordable Care Act: Titles and Sections Addressing Aspects of Reform

Title	*Title Name*	*Sections of the ACA*
Title I	Quality, Affordable Health Care for All Americans	1001–2995
Title II	The Role of Public Programs	3001–3129
Title III	Improving the Quality and Efficiency of Health Care	3131–3602
Title IV	Prevention of Chronic Disease and Improving Public Health	4001–4402
Title V	Health Care Workforce	5001–5701
Title VI	Transparency and Program Integrity	6001–6801
Title VII	Improving Access to Innovative Medical Therapies	7001–7103
Title VIII	Community Living Assistance Services and Supports	8001–8002
Title IX	Revenue Provisions	9001–9023
Title X	Strengthening Quality, Affordable Health Care for All Americans	10101–10909

Source: Adapted from “An Act: The Patient Protection and Affordable Care Act.” The Patient Protection and Affordable Care Act, Pub. L. No. 111-148, §2702, 124 Stat. 119, 318-319 (2010), US Government Printing Office. Because of myriad new bills and resolutions constantly occurring with the ACA, one may read the ACA by visiting this Web site: The Patient Protection and Affordable Care Act, 42 USC § 18001 (2010). US Government Printing Office. “HealthCare.gov” (cited 2020 March 12) on the Internet at: https://www.healthcare.gov/where-can-i-read-the-affordable-care-act/.

Health Insurance Exchanges

A health insurance exchange is an online store where consumers can compare and buy health insurance plans. Each US state had the option to run its own exchange, to work in partnership with the federal government to run an exchange, or to use a federal exchange. Since 2008, the Health Insurance Exchange has helped more than 16 million people find affordable health plans. Each exchange agrees to do the following:

- Present benefit options in a standard format so it's easy for consumers to compare plans
- Operate a toll-free hotline where consumers can ask questions and get help
- Set up a navigator program to help consumers understand and purchase health insurance
- Certify the health plans that sell policies through the exchange and make sure health plans comply with regulatory standards and requirements
- Provide an online calculator so consumers can determine their costs; the calculator will factor in tax credits or subsidies available to the consumer
- Interact with other computer systems and databases to determine whether consumers are eligible for tax credits or subsidies on the exchange or whether they qualify for Medicaid or the Children's Health Insurance Program (CHIP); this is called "no wrong door," and it will make it much easier for consumers to sign up for some kind of health coverage
- Certify which individuals are exempt from the individual mandate

Source: Healthinsurance.org, "What is a health insurance exchange?" (cited 2020, Jan 19), on the Internet at: https://www.healthinsurance.org/faqs/what-is-a-health-insurance-exchange/.[141]

The online marketplace for state insurance exchanges is also known as the Obamacare Health Insurance Exchange Marketplace. Consumers can locate their marketplace through the Obamacare Facts: State Health Insurance Exchange Web site available at: https://obamacarefacts.com/state-health-insurance-exchange/HealthCare.gov which was established to assist Americans in identifying coverage options, obtaining answers to questions, and enrolling in Platinum, Gold, Silver, or Bronze marketplace insurance programs. These plans offer different coverage levels, which differ by cost-sharing requirements.[139]

Relevant to the Diabetes Care and Education Specialist

This summary is intended to help the DCES obtain a general idea of what is contained in Title I. Being familiar with the contents of this section can facilitate communications with Case Managers and Social Workers who make up part of the interprofessional team charged with caring for persons with diabetes. A comprehensive summary of essential health benefits includes the following general categories that apply to diabetes coverage and treatment: ambulatory care, emergency services, hospitalization, maternity and newborn care, mental health and substance use disorders, behavioral health treatment, prescription drugs, rehabilitative and habilitative services and devices, laboratory services, preventive/wellness chronic disease management, and pediatric services, including oral and vision care.[142] The online National Diabetes Prevention Program Coverage Toolkit was developed to provide information about the mechanics of covering the year-long, evidence-based National Diabetes Prevention Program developed by the Centers for Disease Control.[143]

Title II: Role of Public Programs

Section 2703 outlines provisions for health homes for enrollees with chronic conditions. The term *health home* is defined as a designated individual provider or a health-care team selected by eligible individuals with chronic conditions. The term *chronic conditions* includes, but is not limited to, diabetes (Sec. 2703). Health home providers provide a cadre of services, including comprehensive care management, care coordination, and health promotion. Health services also encompass comprehensive transitional care (eg, follow-up from inpatient to other settings; patient and family support; referral to community and social support services, if relevant; and use of health information technology to link services, as feasible and appropriate). The ACA defines a "designated health provider" as a physician, clinical practice or clinical group practice, rural clinic, community health center, community mental health center, home health agency, or any other entity or provider (eg, pediatricians, gynecologists, obstetricians) that is determined by the state to be qualified to be a health home for eligible individuals with chronic conditions.

The ACA has improved access to Medicaid for the lowest-income populations, including coverage for children formerly place in foster care. Special adjustments are considered for certain states recovering from a major disaster. Enhanced support is available for the Children's Health Insurance Program (CHIP), and between fiscal years 2014 and 2019, states received a 23-percentage point increase in the CHIP federal match rate, subject to a 100% cap. Using authority described in the ACA, the Centers for Medicare & Medicaid Services (CMS) launched demonstration projects designed to better manage benefits and care for low-income and disabled Americans.[144] In an effort to improve the quality of Medicaid for both consumers and providers, various sections address fair health insurance premiums, adult health quality measures, payment adjustment for healthcare-acquired conditions, provision of health homes for enrollees with chronic conditions, and demonstration projects, such as the *Independence at Home Medical Practice Demonstration Program*. Under this demonstration, the CMS works with medical practices to test the effectiveness of comprehensive primary services delivery at home, and if doing so improves care for Medicare beneficiaries with multiple chronic conditions.[145] Of special note, the ACA has incorporated protections for American Indians and Alaska Natives containing special rules relating to Native Americans, including the elimination of sunset for reimbursement for all Medicare Part B services furnished by certain Indian hospitals and clinics.

Relevant to the Diabetes Care and Education Specialist

Subtitle F (Sec. 2501), Medicaid Prescription Drug Coverage, is of interest to the DCES as it addresses prescription drug rebates, the elimination of the exclusions of coverage for certain drugs, and provision of adequate pharmacy reimbursement. The DCES may wish to review the table of contents for the ACA, then query for specific items of interest by clicking ctrl + F and entering the topic of interest to quickly locate this information.

The DCES may also wish to monitor the timeline and updates for the *Independence at Home Medical Practice Demonstration Program.*[145] A model summary for this initiative is available on the Internet at https://innovation.cms.gov/initiatives/independence-at-home/. The demonstration rewards providers who deliver high-quality care while reducing costs.

Title III: Improving the Quality and Efficiency of Health Care

The ACA will make substantial investments to improve quality and delivery of care, supporting research to inform consumers about outcomes resulting from differing approaches to treatment and care delivery, via new care models. Payments will be linked to quality outcomes under the Medicare program, with a national strategy designed to improve healthcare quality through quality measure development, measurement, data collection, and reporting. Diabetes-specific information is available biennially through the Diabetes Report Card on the US Department of Health and Human Services, CDC Web site at: https://www.cdc.gov/diabetes/library/reports/reportcard.html.[4] Improvements in rural care and payment accuracy will occur, and the Medicare Part D prescription drug benefit will be expanded, with a reduction in the "donut hole" (a gap in prescription coverage that occurs once all deductibles and co-payments have been met).[146]

Relevant to the Diabetes Care and Education Specialist

Using cross-sectional data from the 2009 and 2016 National Health Interview Surveys (NHIS), Casagrande and colleagues (2018) examined national changes in costs and health insurance coverage before and after implementation of the ACA in a sample of US persons with diabetes, aged 18 to 64 (N=6,220).[138] They concluded that health insurance coverage increased significantly ($p<0.001$) after implementation of the ACA, and that medical costs decreased among lower-income families ($p=0.004$). DCESs are focused on improving outcomes. Current evidence already suggests that although Medicare recipients receiving diabetes care and education are more likely to receive preventive services, DSMES is an underutilized service.[142,147] Despite the discontinuation of many community-based public health programs, the Prevention and Public Health Fund continues to sustain the innovative National Diabetes Prevention Program.[148,149] Enterprising DCESs have an opportunity to partner with health home providers to address diabetes-specific quality measures (ie, DSMES, foot exams, eye exams, SMBG, A1C testing, and influenza vaccines).

Title IV: Prevention of Chronic Disease and Improving Public Health

Sections 4001 to 4402 of the ACA are designed to better position the nation's healthcare system toward disease prevention and health promotion. The ACA established the Prevention and Public Health Fund to provide expanded, sustained investments in prevention and public health, to improve health outcomes, and to enhance health quality. Since 2012, Congress passed several bills that cut these funds and redirect money to pay for non-public legislative proposals.[150] For fiscal year 2019, allocations for the Prevention and Public Health Fund have earmarked over 60 million dollars for chronic disease self-management and diabetes programs.[150] Additional planned activities include funding for a national resource center and awards for new competitive grants to help older adults and adults with disabilities from underserved areas and populations (including Tribal communities) better manage their chronic conditions by providing access to evidence-based chronic disease self-management programs, and to assist grantees with developing and implementing strategies for sustainable program funding beyond the scope of the grant period.[149] Nutrition labeling is required for standard menu items at chain restaurants, and funding will be available for the childhood obesity research.[151]

Section 4108 of the ACA, Incentives for prevention of chronic diseases, specifies that states shall be awarded grants to carry out initiatives to provide incentives to Medicaid beneficiaries who successfully participate in a program and, upon completion of such participation, demonstrate changes in health risks and outcomes, including the adoption and maintenance of health behaviors by meeting established measurable standards and health status targets. The purpose of these initiatives is to test approaches that may encourage behavior modification and determine scalable solutions. In general, a "program" is comprehensive, evidence based, widely available, easily accessible, and designed and uniquely suited to address the needs of Medicare beneficiaries; additionally, it has demonstrated success in helping individuals achieve one or more of the following from Section 4108:

- Cease use of tobacco products
- Control or reduce weight
- Lower cholesterol
- Lower blood pressure
- Avoid the onset of diabetes, or in the case of someone with diabetes, improve the management of the existing condition

In general, grants shall be awarded to state or local health departments and Indian tribes to carry out pilot programs to provide public health community interventions, screenings, and, where necessary, clinical referrals for individuals who are between 55 and 64 years of age (Sec. 4202). In addition to community-wide public health interventions, a state or local health department will be mandated to use funding received in conducting ongoing health screening to identify risk factors for cardiovascular disease, cancer, stroke, and diabetes among individuals in both urban and rural areas who are between 55 and 64 years of age (Sec. 4202). Individuals who are found to have chronic disease risk factors through these screening activities will receive clinical referral/treatment for follow-up services to reduce risk. With respect to individuals with risk factors for or having heart disease, stroke, diabetes, or any other condition for which they were screened, grantees shall determine whether these individuals are covered under a public or private health insurance program. Insured individuals will be referred to an in-network provider, with respect to the program involved. Uninsured individuals can be assisted in determining eligibility for available public coverage options and identifying other appropriate community healthcare resources and assistance programs (Sec. 4202).

Relevant to the Diabetes Care and Education Specialist

Diabetes care and education specialists have an opportunity to partner with state or local health departments as direct providers or as consultants. Community-based resources may need to be developed to serve the collective needs of individuals with or at risk for diabetes as they work to reduce risks and/or improve all aspects of control.

Title V: Health Care Workforce

The ACA originally promised to encourage innovation in healthcare workforce training, recruitment, and retention through the creation of the National Health Care Workforce Commission,[152] designed to support increasing the supply of healthcare workers. However, Congress has not allocated funding to the commission.[152]

Relevant to the Diabetes Care and Education Specialist

The CDC established the NDPP, targeted to adults at high risk for diabetes, to reduce or eliminate the consequences associated with type 2 diabetes. The NDPP includes a grant program for community-based diabetes prevention program model sites, a program which determines eligibility of entities to deliver community-based diabetes prevention services, a training/outreach program for lifestyle intervention instructions, evaluation, monitoring, technical assistance, and applied research carried out by the CDC. The CDC maintains a searchable national registry of recognized diabetes prevention programs that have agreed to follow standards and requirements for recognition as outlined in the CDC-approved curriculum.[116,153] Diabetes care and education specialists interested in offering a lifestyle change program to delay or prevent type 2 diabetes may be interested in learning more about the NDPP Diabetes Prevention Recognition Program (DPRP).[116,153] Training for lifestyle coaching is available through the Association for Diabetes Care and Education Specialists, https://www.diabeteseducator.org/prevention/lifestyle-coach-training).

The diabetes education specialty has long been populated primarily by nurses and dietitians. The former group is in a state of impending critical shortage. A workforce analysis commissioned by the ADCES projected a significant increase in the demand for diabetes care and education specialists through 2025.[147] The analysis identified all healthcare professions, including nursing, as continued sources of DCES. Therefore, having programs that support the education and training of nurses provides an ongoing source of trained professionals who can migrate into the field of diabetes care and education. To sustain and grow the specialty, current diabetes care and education specialists have an obligation to serve as models and mentors for new professionals entering the field. Preventive initiatives in the Affordable Care Act include increased loans and decreased fees associated with federal student loans for physicians, nurses, members of the National Health Service Corps, and the public health workforce.[154]

Title VI: Transparency and Program Integrity

Transparency implies open communication and accountability, thereby operating in a way that allows others to easily see actions being performed. Title VI addresses physician ownership, nursing home transparency of information, improving staff training, and patient-centered outcomes research and its coordinating council for comparative effectiveness research. Medicare, Medicaid, and CHIP program integrity provisions are described in Sections 6301 to 6607 of the ACA. The Elder Justice Act, enacted as part of the ACA, was the first piece of legislation passed to authorize funding to raise awareness for the prevention and elimination of elder abuse, neglect, and exploitation, particularly in long-term care facilities.

Relevant to the Diabetes Care and Education Specialist

According to the interpretation given by the Department of Health and Human Services, this section of the law is aimed, in part, at promoting more effective provider-patient relationships.[139] Improved transparency and improved communication can be linked to the engaged, activated patient. Diabetes care and education specialists, with their expertise in chronic care management, are well positioned to serve as resources and consultants for agencies working to bring more transparency into their processes.

Title VII: Improving Access to Innovative Medical Therapies

The ACA makes a provision for biologics price competition and innovation under Sections 7001 to 7003 and allows for more affordable medicines for children and underserved communities through the 340B program. Title VII of the ACA extends drug discounts to hospitals and communities serving low-income patients and makes a pathway for the creation of generic versions of biological drugs, improving access to effective, lower-cost alternatives.

Relevant to the Diabetes Care and Education Specialist

The intent of this section is to enhance access to medications by making them more affordable. Diabetes care and education specialists have long advocated, individually and in the aggregate, for underserved populations to have access to *all* diabetes medications and devices. Price competition brings with it a potential for compromised quality. Diabetes care and education specialists have an opportunity to serve as a watchdog group to ensure that as access to medications improves, quality does not deteriorate.

Title VIII: Community Living Assistance Services and Supports

The ACA established a national voluntary insurance program, the Community Living Assistance Services and Supports (CLASS) Independence Benefit Plan, for the purchase of community living assistance services and support. The intent was to provide a mechanism for beneficiaries to live as independently as possible in their own homes or a residential facility of choice. In 2011, the Obama administration elected to drop this long-term health program.[155]

Relevant to the Diabetes Care and Education Specialist

Title VIII is specific to development and enrollment issues rather than provider-linked services. However, diabetes care and education specialists who are actively engaged with the older adult population should be aware of Title VIII and its intent to ensure that beneficiaries have access to the equipment and services needed for independent living.

Title IX: Revenue Provisions

The ACA was designed to, when fully enacted, ultimately reduce the federal deficit. Title IX outlines tax cuts to citizens as well as the consequences for insurance companies and plan administrators, and it specifies the taxes and fees imposed on agencies and industry.

Relevant to the Diabetes Care and Education Specialist

Section 9003 is of specific interest to diabetes care and education specialists, in that it specifies distributions for medicine are qualified only if they are for prescribed drugs or insulin. An annual fee can be imposed on manufacturers and importers of branded pharmaceuticals and on medical devices. To remain informed about changes, the DCES may be interested in reviewing the complete law, latest statistics, and Republican counterproposals for additional updates.[156]

Title X: Strengthening Quality, Affordable Health Care for All Americans

Sections 10101 to 10909 address revisions, modifications, clarifications, expansions, and amendments made to the original ACA.

Relevant to the Diabetes Care and Education Specialist

Section 10407 may be cited as the Catalyst to Better Diabetes Care Act of 2009 and includes provisions for a national diabetes report card, prepared biennially in collaboration with the CDC. In general, each report card includes aggregate health outcomes related to individuals diagnosed with diabetes or prediabetes, including preventive care practices, quality of care, risk factors, and outcomes. Each report card includes trend analysis for the nation and, to the extent possible, for each state, for the purpose of tracking progress in meeting established national goals and objectives for improving diabetes care, costs, and prevalence and informing policy and program development. The report card is available to the public and is posted on the CDC's Web site (https://www.cdc.gov/diabetes/prevention/index.html).[4]

Also under this section is a mandate for improvement of vital statistics collection, which promotes the education and training of physicians on the importance of birth and death certificate data and how to properly complete these documents, including the collection of such data for diabetes and other chronic diseases. In carrying out this subsection, improvements may be promoted for the collection of diabetes mortality data, including the addition of a question for the individual certifying the cause of death regarding whether the deceased had diabetes. The National Academy of Medicine (formerly called the Institute of Medicine) and appropriate associations and councils will collaborate to conduct a study of the impact of diabetes on the practice of medicine in the United States, and the appropriate level of diabetes medical education that should be required prior to licensure, board certification, and recertification (Sec. 10407). Bright and Sakurada outline a population health approach, involving personal health care professionals and quality improvement interventions believed to be effective in improving diabetes care. These interventions include education and support and provider role changes such as expanding the role of pharmacists, nurses, multidisciplinary teams, and the use of telemedicine.[157]

Also under Title X, Section 10401: Centers of Excellence for Depression is a provision specifying that each national center shall collaborate with other centers to carry out general activities that foster communication with other providers attending to co-occurring physical health conditions such as cardiovascular disease, diabetes, cancer, and substance abuse disorders.

Summary

As a result of the ACA, persons with diabetes will not be penalized for having a preexisting condition and can expect reduced healthcare expenses due to annual caps for out-of-pocket spending. Individuals with diabetes are able to select a plan best suited to their needs, obtain coverage for preventive health screenings and, over time, experience fewer health disparities.

Relevant to the Diabetes Care and Education Specialist

These provisions include insurance components, diabetes prevention, chronic disease management, and improved standards and reporting mechanisms. Some of these provisions became effective in 2014 while others continue to be rolled out. The ACA is a comprehensive law that receives ongoing revision, modification, clarification, expansions, and amendments. To track the status of this law, readers are encouraged to query for updates on the Patient Protection and Affordable Care Act, Public Law 111-148 by visiting Congress.gov on the Internet at https://www.congress.gov. At the time of this writing, the Office of Disease Prevention and Health Promotion-National Clinical Care Commission is seeking comments about federal diabetes prevention and treatment programs. The Diabetes Care and Education Specialist may wish to monitor the activity of the Commission and review the final report—anticipated October 2021.The World Healthcare Organization defines health care policy as specific plans, actions, and decisions that are committed to attain health care goals within a society.[158]

Diabetes: Advocating for Policy Change

In the United States, the soaring costs linked to diabetes management make it imperative to adopt local and national policies addressing programs, plans, and services that can reduce the burden diabetes places on individuals and society at large.

Advocacy for diabetes can be broken down into four levels: (1) individual, (2) community, (3) national, and (4) international. The impact of policy work can be seen at each of these levels. In the community, a key goal is to improve situations for individuals locally who face barriers and challenges associated with diabetes management. Local challenges might be lack of access to food markets, school systems without nurses or other staff trained to assist children with diabetes, or lack of clean water. A current problem gaining considerable attention is the escalating cost of insulin.[159] Individuals can contact government officials at the state and federal levels about changes that need to be made in policies for people with diabetes.[160] While the battle surrounding the cost of insulin is far from over, an excellent example of local policy change can be found in the state of Colorado. Colorado was the first state in the nation to cap the cost of insulin in 2019 by passing House Bill 1216: Reduce Insulin Prices Bill.[161] This seemingly enormous task was accomplished through the efforts of community organizers and state legislators. At the federal level, advocacy is centered around influencing policies that impact individuals across the nation. As noted in the previous section, The Diabetes Prevention Act, launched in 2009, resulted in the establishment of the National Diabetes Prevention Program. This program aims to raise awareness of diabetes risk and assist people at high risk of developing diabetes to utilize evidence-based lifestyle change interventions.[162] Lifestyle change programs, now available in hundreds of locations throughout the nation, are frequently offered by DCES.[163]

An easy way to engage with federal representatives is to see whether they are members of the diabetes caucus, a large and influential body of legislators who are knowledgeable about diabetes.[164] An issue at the heart of diabetes care and education is the Expanding Access to DSMT Act, designed to reduce barriers and improve Medicare beneficiary access to DSMT services.[165–168] At the international level, advocacy has been seen to be focused on raising awareness on the impact that diabetes brings on a global scale. Financial efforts are made to bring resources to those who lack the resources to manage their diabetes. The International Diabetes Federation has been a global champion for advocacy. Some of their remarkable advocacy activities include the 2006 United Nations Resolution on Diabetes, and the 2011 IDF Road Map Programme. Both efforts challenged leaders to understand the devastation diabetes can cause by encouraging them to gain a more holistic understanding about the chronic disease as well as highlighting the urgency for funding proper resources.[160] It is easy to be overwhelmed by the enormity of what needs to be changed in diabetes. Former Speaker of the House, the late Tip O'Neill (1912–1994), coined the phrase "all politics is local," and while some may question the veracity of this statement in contemporary times, the impact of individual advocacy efforts cannot be minimized. At the individual level, advocacy can translate into improved care at the community, national, and international levels. One needn't look too far to find advocacy resources. Organizations such as the Academy for Nutrition and Dietetics, the American Diabetes Association, the Association for Diabetes Care and Education Specialists, and the JDRF (formerly the Juvenile Diabetes Research Foundation) all have advocacy arms, each with a focused agenda. There are also advocacy groups organized by and for persons with diabetes. One such group, the Diabetes Patient Advocacy Coalition (DPAC), is dedicated to the promotion and support of public policy initiatives that improve the health of people with diabetes (https://diabetespac.org/). The DCES is in a perfect position to keep informed about local, national, and international advocacy efforts and to use networking skills to engage with others.

Advocacy is crucial to promote change within a society, but it is imperative that the message being conveyed to legislatures, healthcare organizations, providers, professional groups, and other stakeholders is centered around strong evidence. To achieve and maintain a high level of evidence, continuous research is needed to evaluate how current policies and programs are impacting individuals with diabetes from a prevention, self-management, and healthcare utilization cost perspective.[169] Updated data highlighting best evidence is instrumental in supporting policies that are renewed on an annual basis, preferably through meta analyses and systematic reviews. While the highest level of evidence is essential for effective policy work, it is crucial for both professional and government organizations to align their evidence in order to fully translate research into practice.[162]

Focus on Education

Teaching Points

Diabetes can be viewed as a syndemic, a combination of health or social conditions that interact to increase the disease burden to a community, further developing a public health concern. A comprehensive approach to diabetes care is needed to minimize its negative social impact. Disease management strategies and the Chronic Care Model (CCM) might be used to improve access to diabetes care and education and provide systemic self-management support. Successful disease management includes diabetes care, education, and support to facilitate healthy lifestyle behaviors.

One in every 3 individuals born today will develop diabetes during his or her lifetime. Worldwide, the largest increases are expected in countries where resources are most limited. The incidence of type 2 diabetes is increasing in children of Native American, Hispanic, African American, or Pacific Islander ancestry, especially in those who are overweight or obese. Type 2 diabetes represents 90% to 95% of all cases of diabetes worldwide. Currently more than 1 in every 7 dollars from the US economy is used to pay for the costs linked to diabetes.

Diabetes self-management support refers to the activities that assist the person with prediabetes or diabetes in implementing and sustaining the behaviors needed to manage his or her condition on an ongoing basis beyond or outside of formal self-management training. The type of support provided can be behavioral, educational, psychosocial, or clinical.

Diabetes care and education specialists are the primary providers of DSMES. They are involved in direct care of those with diabetes, prediabetes, and related conditions; population health management, education of other healthcare professionals, research, social reform, and advocacy. Some educators obtain certification and are credentialed as a CDCES®, a BC-ADM®, or both. The work of the diabetes care and education specialist is supported by many others on the healthcare team. Competencies guide the development, practice, and career paths of healthcare professionals involved in diabetes care and education.

Healthy People 2020 targets related to diabetes remain essentially the same as the Healthy People 2010 targets because the percentage of individuals receiving formal diabetes education failed to reach the goal of 60%. Barriers to access continue to be a primary challenge in providing diabetes education.

Health Literacy

Health literacy is a multifactorial phenomenon that involves individuals, families, communities, and systems. When addressing health literacy, consider access to care and resources; the knowledge, skills, and abilities of everyone involved; the culture of healthcare providers and public health systems; and demographics.

The Patient Protection and Affordable Care Act of 2010 addresses health literacy both directly within 4 provisions and indirectly in the following broad themes:

- *Coverage expansion:* Enrolling, reaching out to, and delivering care to health insurance coverage expansion populations since 2014
- *Equity:* Ensuring equity in health and health care for all communities and populations
- *Workforce:* Training providers on cultural competency and diversifying the healthcare provider workforce
- *Patient information:* At appropriate reading levels in print and electronic media
- *Public health and wellness*
- *Quality improvement:* Innovation to create more effective and efficient models of care, particularly for individuals with chronic illnesses requiring extensive self-management

The Hospital Consumer Assessment of Healthcare Providers and Systems Survey—also known as Hospital CAHPS®, developed by the CMS, along with the Agency for Healthcare Research and Quality (AHRQ)—addresses health literacy and numeracy issues through survey questions on doctor and nurse communication, communication about medicines, and discharge information.

Focus on Practice

Improve care and enhance quality by facilitating and critically considering feedback from all individuals regarding coordination of their care. People with diabetes and related conditions choose where and how they want their DSMES and other services. Continuous quality assurance will allow program managers to evaluate the quality of systems and person-centered interventions.

Effectively communicate around all clinical care services. Use the title diabetes care and education specialist to communicate with stakeholders about DSMES and the breadth of services you can provide. Ensure follow-up with all persons involved in the process. Individually and collectively advocate for the services you provide.

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