2017 National Standards for Diabetes Self-Management Education and Support

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Introduction

By the most recent estimates, 29.1 million people in the U.S. have diabetes. Twenty-one million have been diagnosed with diabetes and 8.1 million are believed to be living with undiagnosed diabetes. At the same time, 86 million people are estimated to have blood glucose levels that show increased risk for diabetes. Thus, more than 115 million Americans are at risk for developing the devastating complications of diabetes (1).

Diabetes self-management education and support (DSMES) is a critical element of care for all people with diabetes and those at risk for developing the disease. It is necessary to learn how to manage diabetes and prevent or delay the complications (2) (3) (4) (5) (6) (7) (8). The National Standards for Diabetes Self-Management Education and Support (Standards) are designed to define quality DSMES and assist those who educate to implement evidence-based DSMES. The Standards are applicable to educators in solo practice as well as those in large multicenter programs, care coordination programs, population health programs, and technology enabled models of care (9). By following the Standards, DSMES should be incorporated in new and emerging models of care, including virtual visits, Accountable Care Organizations, and patient-centered medical homes (10). The Standards do not endorse any one approach, but rather seek to delineate the commonalities among effective and evidence-based DSMES strategies. These Standards are used in the field for recognition by the American Diabetes Association (ADA) and accreditation by the American Association of Diabetes Educators (AADE). They also serve as a guide for non-accredited and non-recognized providers of DSMES.

Because of the dynamic nature of health care and diabetes-related research, the Standards have previously been reviewed and revised approximately every five years by key stakeholders and experts within the diabetes care and education community. Given the rapidly changing health care environment and the ever-growing field of technology, the 2017 Standards Review...
Task Force recognizes the potential need to review the literature for evidence-driven updates more frequently in the future as advances in health care delivery are evolving. In 2016, the task force was jointly convened by AADE and ADA. Members of the task force included experts from numerous health care professional disciplines and individuals with diabetes. Representatives from public health, those practicing with underserved populations including rural primary care and other rural health services, virtual, pharmacy, insurer programs, individual practices, large urban specialty practices, and urban hospitals participated on the Task Force. The Task Force was charged with reviewing the current National Standards for DSMES for appropriateness, relevance, scientific basis and updating them based on the available evidence and expert consensus.

Although the term “diabetes” is used predominantly, the Standards should also be understood to apply to the education and support of people at risk for diabetes. DSMES programs are well-equipped to educate individuals with either of these health assessments, as they offer strategies for supporting successful lifestyle change, self-management, and healthy behaviors. The National Diabetes Prevention Program (National DPP) is an evidence-based program designed for people diagnosed with prediabetes (11). The National DPP and DSMES co-located within organizations have been found to be successful and the outcome of this partnership allows for the sharing of expertise and the easy transition from one service to another (12). This revision of the Standards highlights the focus of the individual affected by, or at risk for, diabetes as the center of their care team, recognizing that the person affected by diabetes spends less than 1 percent of their life with their health care team accessing services. Thus, the focus of the Standards needs to include helping the person affected by diabetes to develop problem solving skills and attain ongoing decision-making support necessary to self-manage diabetes. In addition, encouraging e-health tools and online peer support will allow for the implementation of a complete feedback loop essential to facilitate on-going self-management (13) (14) (15). Diabetes also carries with it a risk for burnout, which, as it develops, can lead to poorer health outcomes (16). We must consider the burden of treatment placed upon those affected by diabetes — in essence, the “work of being a patient” — and consider all decisions within the lens of the individual’s capacity (17). All DSMES services must focus on the priorities, concerns, and preferred delivery method and timing of the individual incorporating a patient-centered approach.

Previous Standards have used the term DSMES “program;” however, when focusing on the needs of an individual, this term is no longer relevant. The use of DSMES services more clearly delineates the need to individualize and identify the elements of DSMES appropriate for an individual. This revision encourages providers of DSMES to embrace a contemporary view of the new complexities of the evolving health care landscape (18).

STANDARD 1

Internal Structure
The provider(s) of DSMES will define and document a mission statement, goals, and where the DSMES services are incorporated within the organization; large, small, or independently operated.

Documentation of a defined structure, mission, and goals supports effective provision of DSMES. Mission defines the core purpose of the organization and assists in developing professional practice and services. Business literature, case studies, and reports of successful organizations emphasize the importance of clear shared missions, goals, and defined relationships (19) (20). The absence of these common goals and relationships is cited as one barrier to success (20). Defined leadership is needed to remove any service-related obstacles and find resources to advance DSMES services (21). Therefore, entities providing DSMES services must develop lines of communication and support to be clear on their mission, outcomes, and quality improvement measurement (22). The chronic care model components support the need for documented organizational mission and goals (21).

According to the Joint Commission, documentation of an organization’s structure is equally important for both small and large health care organizations (23). Providers of DSMES working within a larger organization will have the organization document recognition and support of quality DSMES as an integral component to their mission (23). For smaller or independent providers of DSMES, the organization will identify and document its own appropriate mission, goals, and structure to fit the function in the community it serves (22).

STANDARD 2
Stakeholder Input

The provider(s) of DSMES will seek ongoing input from valued stakeholders and experts to promote quality and enhance participant utilization.

The goal of seeking stakeholder input in the ongoing planning process is to gather information and foster ideas that will improve the utilization, quality, measurable outcomes, and sustainability of the DSMES services. Stakeholders can be identified from DSMES participants, referring practitioners, community-based groups that support DSMES, and health care professionals (both within and outside of the organization) who provide input to promote value, quality, access, and increased utilization (24) (26).

Social determinants related to the population served will be used to guide stakeholder selection and facilitate the connection between the DSMES services, the participant population, the health care providers, and the community (27) (28).

A planned, documented strategy to engage and elicit input from stakeholders will shape how DSMES is developed, utilized, monitored, and evaluated (29) (18) (21) (26). If the provider of DSMES is experiencing a lack of referrals or low utilization, the stakeholders can assist with the solution (30) (31). The goal is to provide effective and dynamic DSMES services that are patient-
centered, culturally relevant, and responsive to the referring practitioner and participant-
identified needs (27), ultimately engaging participants in life-long learning (29) (25).

STANDARD 3

Access to Population Served

The provider(s) of DSMES will assess the communities they serve to determine the resources,
design, and delivery methods that will align with the population’s need for DSMES services.

Currently, the majority of people with and at risk for diabetes do not receive DSMES (32) (33)
(34) (35). While there are many barriers to DSMES, one crucial issue is access (36) (37).
Providers of DSMES, clarifying the specific populations they are able to serve, must understand
their community and regional demographics (37) (38) (39) (40) (41) (42).

Individuals, their families, and communities require education and support options and tools
that align with their needs (43) (44) (45). The provider(s) of DSMES must ensure the necessary
educational alternatives are available (43) (46). Understanding the population’s demographic
characteristics, including ethnic/cultural background, sex, age, levels of formal education,
literacy and numeracy (47) (48) (49) (50) as well as perception of diabetes risk and associated
complications is necessary (35).

It is essential to identify the barriers that prevent access to DSMES during the assessment
process. (51) (52) (53). Individuals’ barriers may include socioeconomic or cultural factors,
participant schedules, health insurance shortfalls, perceived lack of need, and limited
encouragement from other health care practitioners to engage in DSMES (54) (55) (56) (57) (9)
(58).

Models that include population health and disease management, a multi-disciplinary team, and
ongoing social support improve both practice and individual outcomes (59) (60) (61). Medical
management integrated with DSMES improves access, clinical outcomes, and cost-effectiveness
(62) (63). Creative solutions incorporating technology to increase reach and engagement must
be examined (64) (65). Telehealth, electronic health records (EHR), mobile applications and
cognitive computing will proactively identify and track participants while offering endless
opportunities for personalized and contextualized DSMES (66) (67) (68) (69).

STANDARD 4

Quality Coordinator Overseeing DSMES Services

A quality coordinator will be designated to ensure implementation of the Standards and oversee
the DSMES services. The quality coordinator is responsible for all components of DSMES,
including evidence-based practice, service design, evaluation, and continuous quality improvement.

Ensuring quality is an essential component of the chronic care model. Patient-centered health care is associated with improved outcomes (70) (71) (72) and better relationships between referring practitioners, individuals, and teams (73) (74). For DSMES services to be sustainable, quality must be a priority (71).

Most importantly, the quality coordinator is charged with collecting and evaluating data to identify gaps in DSMES, providing feedback on the performance of the DSMES services to team members, referring practitioners and the organization’s administration. The use of EHR and person-centric software improves care (75) (76) (77) (78) (79) (80) (81) and assists the quality coordinator in evaluating the effectiveness of DSMES. The quality coordinator utilizes data mining to inform payers and members of the health care team of the clinical outcomes of DSMES. Although the quality coordinator does not require additional degrees or certifications in informatics, understanding these skills as well as marketing, health care administration, and business management are helpful. The quality coordinator does need experience in the process of identifying, analyzing, and communicating quality data. The quality coordinator must have continuing education annually as it relates to the assessment, implementation and evaluation of the DSMES services and must include continued education specific to diabetes if the quality coordinator also educates.

STANDARD 5

DSMES Team

At least one of the team members responsible for facilitating DSMES will be a registered nurse, registered dietitian, or pharmacist with training and experience pertinent to DSMES, or be another health care professional holding a certification as a diabetes educator (CDE®) or Board Certification in Advanced Diabetes Management (BC-ADM). Other health care workers or diabetes paraprofessionals may contribute to DSMES with appropriate training in DSMES and with supervision and support by the team members listed above.

The evidence supports a multidisciplinary team approach to diabetes care, education, and support (82). Current research continues to support nurses, dietitians, and pharmacists as providers of DSMES responsible for curriculum development (83) (84) (85) (86) (87) (88).

Expert consensus supports the need for specialized clinical knowledge in diabetes and behavior change principles for DSMES team members (89). Certification as a CDE® (National Certification Board for Diabetes Educators [NCBDE]) or BC-ADM (AADE) demonstrates specialized training beyond basic discipline preparation and mastery of a specific body of knowledge. All DSMES team members must document appropriate continuing education of diabetes-related content, ensuring their continuing competence in their respective roles.
Registered nurses, registered dietitians, pharmacists, and health care disciplines that hold a certification as a CDE® or BC-ADM can perform all the DSMES services including clinical assessments (90) (91). Paraprofessionals with additional training in DSMES effectively contribute to the DSMES team. Diabetes paraprofessionals can assist in education, reinforce self-management skills, support behavior change, facilitate group discussion, provide psychosocial support and ongoing self-management support. Paraprofessionals must receive continuing education specific to the role they serve within the team and must directly report to the quality coordinator or one of the qualified DSMES team members (92) (93) (94) (95) (96) (97) (98).

For services outside the expertise or scope of the DSMES provider, a mechanism must be in place to ensure that the participant is given the information needed to be referred to the appropriate health care professionals (89) (99).

STANDARD 6

Curriculum

A written curriculum reflecting current evidence and practice guidelines, with criteria for evaluating outcomes, will serve as the framework for the provision of DSMES. The needs of the individual participant will determine which elements of the curriculum are required.

Individuals with or at risk for diabetes, and those supporting them, have much to learn to enable effective self-management. DSMES provides this education in an up-to-date, evidence-based, and flexible curriculum (100) (101). The options for delivery of the curriculum have grown dramatically as technology has been incorporated into health care.

The curriculum is the evidence-based foundation from which the appropriate content is drawn to build an individualized education plan based on each participant’s concerns and needs. The curriculum content must be supplemented with appropriate resources and supporting education materials. A curriculum also specifies effective teaching strategies and methods for evaluating learning outcomes (102) (103). The curriculum must be dynamic (103) (104) (105) (106) (107). Recent education research endorses the inclusion of practical problem-solving approaches and collaborative care, addressing psychosocial issues, behavior change, and strategies to sustain self-management efforts (108) (109) (60) (110) (111) (112) (113) (114) (115).

The following core content areas demonstrate successful outcomes (116) (3) (5) (101) (3) (117) (118), and must be reviewed to determine which are applicable to the participant:

- diabetes condition process and treatment options;
- healthy eating;
- physical activity;
• medication and device usage;
• monitoring and using patient-generated health data (PGHD);
• preventing, detecting, and treating acute and chronic complications;
• healthy coping with psychosocial issues and concerns; and
• problem solving.

The content areas listed, as well as educating the participant on navigating the health care system, learning self-advocacy, and e-health education (14) (106) (107) (116) (117) (118) (119), can be adapted for all practice settings and provide a solid outline and agenda for a DSMES curriculum. It is crucial that the content be tailored to match individuals’ needs and be adapted as necessary for age, type of diabetes, cultural factors, health literacy and numeracy, and comorbidities (119) (120) (121) (122) (123).

STANDARD 7

Individualization

The DSMES needs will be identified and led by the participant with assessment and support by one or more DSMES team members. Together, the participant and DSMES team member(s) will develop an individualized DSMES plan.

People affected by diabetes engage in DSMES during various stages of their diabetes diagnosis (106) (88). Regardless of the stage, the person affected by diabetes has their own priorities and needs. The DSMES services must be designed using patient-centered care practices, in collaboration with the participant, focusing on their priorities and values (124) (106) (88). The most important element to appreciate is that no participant is required to complete a set DSMES structure. When the participant has achieved their goals, they can determine that their initial DSMES intervention is complete. However, DSMES is an ongoing, lifelong process, with ongoing assessments of AADE7™ self-care behaviors (125), and continual support (25) (106).

Research indicates the importance of individualizing DSMES to each participant (126) (127). The assessment process is collaboratively conducted with the participant, to identify needs and to facilitate the appropriate educational and behavioral interventions, development of problem solving skills, and self-management support strategies (128) (129) (116) (127). The assessment must incorporate information about the individual’s medical history, age, cultural influences, health beliefs and attitudes, diabetes knowledge, diabetes self-management skills and behaviors, emotional response to diabetes, disease burden, ability, readiness to learn, literacy level (including health literacy and numeracy), physical limitations, family support, peer support (in person or via social networking sites), financial status, and other barriers (130) (131) (132) (133) (134).
The DSMES team member(s) will use clear health communication principles, using plain language, avoiding jargon, making information culturally relevant, using language and literacy appropriate education materials, and using interpreter services when indicated (135). Evidence-based communication strategies such as collaborative goal-setting, action-planning, motivational interviewing, shared decision-making, cognitive behavioral therapy, problem-solving, self-efficacy enhancement, teach-back, and relapse-prevention strategies are also effective (115) (136) (137) (138) (139). It is crucial to develop action-oriented behavioral goals and objectives (2) (127) (130) (140). Creative, patient-centered, experience-based delivery methods beyond the mere acquisition of knowledge are effective for supporting informed decision making and meaningful behavior change and addressing psychosocial concerns (141) (125). Incorporating PGHD, especially blood glucose and continuous glucose monitoring data, into decision-making individualizes self-management and empowers participants to fully engage in personal problem-solving to change behavior and improve outcomes (142) (143) (144) (145). There is strong evidence that incorporating text messaging into DSMES interventions improves engagement and outcomes (146) (13) (147) (148). Use of digital technology (cloud-based, telehealth, data management platforms, apps, and social media) enhances the ability to enable a complete feedback loop, engage in 2 way communication, analyze PGHD, customize education and personalize feedback to provide real-time engagement in self-management, as well as enable and empower participants (149) (150) (68) (13).

Reassessment during key times, such as when complicating factors influence self-management and during transitions of care, can determine whether there is need for additional or different DSMES services (25) (151). A variety of assessment modalities, including online assessments via patient portals and EHR, tablet computers that integrate with EHR, text messaging, web-based tools, automated telephone follow-up, and remote monitoring tools may be used (152) (153) (150) (149) (68). Selecting validated tools, used for assessment and ongoing evaluation, will generate more evidence to support DSMES (154). Although not an exhaustive list or applicable to all patient populations, examples of assessment tools can be found in the Standard’s glossary.

The assessment and education plan, intervention, and outcomes will be documented in the participant’s health record. Documentation of participant contact with DSMES team members will guide the education process, provide evidence of communication among other members of the individuals’ health care team, and demonstrate adherence to guidelines, all of which will assist in long-term management of diabetes care and diabetes self-management support (86). Using technology tools will increase access to information for all team members to work collaboratively and have access to documentation.

**STANDARD 8**

**Ongoing Support**
The participant will be made aware of options and resources available for ongoing support of their initial DSMES, and will select the option that best supports their self-management needs.

While initial DSMES is necessary, it is not sufficient for participants to sustain a lifetime of diabetes self-management (25) (109). Initial improvements in metabolic and other outcomes have been shown to diminish after six months (109) (25). To sustain behavior at the level needed to effectively self-manage diabetes, participants need ongoing diabetes self-management support. Ongoing support is defined as resources which help the participant implement and sustain the ongoing skills, knowledge, and behavioral changes needed to manage their condition (25). The vital point is that the participant selects the resource or activity that best suits their self-management needs.

A variety of strategies are available for engaging in ongoing support both within and outside DSMES services. Support can include internal or external group meetings (connection to community and peer groups [online or locally]), ongoing medication management, continuing education, resources to support new or adjustments to existing behavioral goal-setting, physical activity programs, weight loss support, smoking cessation, and psychosocial support among others (155) (156) (157) (158) (159) (160). The effectiveness of providing support through diabetes educators, disease-management programs, trained peers, diabetes paraprofessionals, community-based programs, or through use of technology (text, email, social media, web-based, mobile, digital, and wearable and wireless devices) has also been established (155) (156) (157) (161) (162) (163) (164) (165) (166). Peer support using social networking sites improves glucose management, especially in people with type 2 diabetes (13). Practitioners can highlight the benefits and accessibility of online diabetes communities as a resource to help participants learn from others living with the condition, facing similar issues, available 24 hours a day, 7 days a week, when it is convenient for them to engage. A patient-centered approach is recommended to incorporate ongoing support plans in clinical care (109) (167) (124).

STANDARD 9

Participant Progress

The provider(s) of DSMES will monitor and communicate whether participants are achieving their personal diabetes self-management goals and other outcome(s) to evaluate the effectiveness of the educational intervention(s), using appropriate measurement techniques.

Effective DSMES is a significant contributor to long-term, positive health outcomes and clinical improvement (128). Assessing needs and communicating information and skills that promote effective coping and self-management must involve a personalized and comprehensive approach (25). The provider(s) of DSMES will rely on behavioral goal setting strategies to help participants meet their personal targets (168). There are proven steps based on goal-setting theory that improve outcomes. The role of the DSMES team is to aid the goal-setting process.
and adjust based on participant needs and circumstances (169) (170). Validly measuring the achievement of SMART goals (specific, measurable, achievable, realistic and time-bound) and action planning including an assessment of confidence and conviction is essential (171).

To demonstrate the benefits of DSMES, it is important for DSMES providers to track relevant evidence-based outcomes. The AADE Outcome Standards for Diabetes Education specify behavior change as the key outcome and the AADE7™ Self-Care Behaviors (healthy eating, being active, taking medication, monitoring, problem solving, reducing risk and healthy coping) provide a useful framework for assessment, documentation, and evaluation (103) (125). Providers of DSMES should select validated measurement tools to accurately track participant behavior change including, but not limited to, empowerment, self-care, reduction in weight, quality of life, and/or diabetes distress.

Tracking and communication of individual outcomes must occur at appropriate intervals. The interval depends on the nature of the outcome itself and the time frame specified based on the individual’s personal goals. For some areas, the indicators, measures, and timeframes will be based on guidelines from professional organizations or government agencies (128).

STANDARD 10

Quality Improvement

The DSMES quality coordinator will measure the impact and effectiveness of the DSMES services and identify areas for improvement by conducting a systematic evaluation of process and outcome data.

Formal quality improvement strategies can lead to improved diabetes outcomes (172) (173). DSMES must be responsive to advances in knowledge, treatment strategies, education strategies, and psychosocial interventions, as well as consumer trends and the changing health care environment. By measuring and monitoring both process and outcome data on an ongoing basis, providers of DSMES can identify areas of improvement and adjust participant engagement strategies and service offerings accordingly. Evaluation can contribute to the sustainability of the service. Positive results from quality initiatives can be used in marketing efforts and shared with administration in larger health systems. A focus on quality is also part of overall medical quality initiatives including pay-for-performance and the Medicare Access and CHIP Reauthorization Act (MACRA), which has shifted provider payment based on productivity to one that focuses on quality and outcomes (174).

The Institute for Health Care Improvement suggests three fundamental questions that should be answered by an improvement process: What are we trying to accomplish? How will we know a change is an improvement? And what changes can we make that will result in an improvement (175)?
Once areas for improvement are identified, the DSMES quality coordinator must determine timelines and important milestones, including data collection, analysis, and presentation of results. Measuring a variety of outcomes ensures that change is successful without causing additional problems in the system. Outcome measures indicate the result of a process (i.e., whether changes are leading to improvement, e.g. a change in a behavior or a biomarker [A1C]), while process measures provide information about what caused those results (e.g. if the participant attended DSMES sessions or had an exam done) (175). Process measures are often targeted to those processes that affect the most important outcomes. Measures generally recommended for DSMES services include behavioral measures (e.g. participant’s report of self-management activities and psychosocial behaviors including distress), clinical measures (e.g. changes in weight or A1C), operational measures (e.g. participant satisfaction, financial indicators, no-show rates, or results of marketing efforts), and process measures (e.g. participants receiving services, referral to DSMES or referral or an eye exam). A variety of methods can be used for quality improvement initiatives, such as the Plan Do Study Act model, Six Sigma, Lean, Re-AIM, and workflow mapping, and there are helpful resources available to assist those initiating quality improvement programs for the first time or looking for other options (172) (173) (174) (176).

Works Cited


35. NDEP survey results in press NOT READY FOR PUB YET.


98. —. Practice levels for Diabetes Educators and Diabetes paraprofessionals. 2016.


176. RE-AIM. http://re-aim.org/.


Glossary of Terms

Assessment Tools.

- The Diabetes Distress Scale (short form)
  - A two-question initial screening tool to assess diabetes-specific distress (followed by the full 17-item scale when indicated).
- The WHO-5 Brief Quality of Life survey
  - Validated in many languages, is a reliable measure of emotional functioning and screen for depression and has been used extensively in research and clinical care (177), including the DAWN study (Diabetes Attitudes Wishes and Needs).
- Problem Areas In Diabetes (PAID)
  - A 20-item measure of diabetes-specific distress identifying emotional distress and burden associated with diabetes (178) (pediatric and teen versions are also available) (179) (180).
- Diabetes Self-Efficacy
  - An eight-item self-report scale designed to assess confidence in performing diabetes self-care activities (181).
- Summary of Diabetes Self-Care Activities (SDSCA)
  - An 11-item or expanded 25-item measure of diabetes self-care behaviors (182).

Capacity. The ability a person has to understand and manage their condition.

Cognitive computing. The simulation of human thought processes in a computerized model to mimic the way the human brain works.

Data mining. The ability of a coordinator to aggregate data from within their organization’s documentation system.

Diabetes paraprofessional. A person with a non-medical background who can provide support as part of a diabetes care team.
**Diabetes self-management education and support.** The ongoing process of facilitating the knowledge, skill, and ability necessary for prediabetes and diabetes self-care, and the activities that assist the person with diabetes or prediabetes 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. This process incorporates the needs, goals, and life experiences of the person with diabetes or prediabetes and is guided by evidence-based standards. Support (whether behavioral, educational, psychosocial, or clinical) helps implement informed decision making, self-care behaviors, problem solving, and active collaboration with the health care team and to improve clinical outcomes, health status, and quality of life.

**Disease burden.** The effect a disease takes, whether physically, financially, mentally, or via morbidity and mortality.

**Electronic health records.** The digital version of a patient’s chart. EHRs are available in real time and available to patients and their care team immediately.

**Health care stakeholder.** Anyone involved in or affected by the financing, implementation, or outcome of a service, practice, process, or decision made by another—e.g., health care, health policy. Examples of stakeholders with interest in health care are providers, patients (health care consumers), payers, etc.

**Mission.** Core purpose, direction, and why the organization exists. It describes who it serves and how it does it.

**Patient-generated health data.** Information created or reported by patients or their caregivers to respond to a health issue.