



Diabetes and Disabilities

American Association of Diabetes Educators (AADE) Position Statement

Introduction

Diabetes self-management education and training (DSME/T) is an integral part of diabetes care for all affected persons, including those with disabilities. Many disabilities present barriers either to the DSME/T process or to the ability to carry out necessary self-care tasks. For example, hearing or visual disabilities can cause difficulty accessing necessary information in lectures or print; mental retardation or developmental disabilities can cause difficulty understanding instructions for and remembering to take medication; and decreased manual dexterity can cause difficulty drawing insulin. For individuals with disabilities, DSME/T that is accessible in both process and content is a prerequisite to attaining critical self-management goals in each area defined by the AADE7 Self-care Behaviors™. AADE's Code of Ethics states that diabetes educators provide services with respect for the uniqueness, dignity, and autonomy of each person.¹ The Scope of Practice, Standards of Practice, and Standards of Professional Performance for Diabetes Educators² explicitly acknowledge the significance of barriers presented by disabilities:

The diabetes educator . . . addresses the following topics in the assessment . . . physical factors including . . . *mobility, visual acuity, hearing, manual dexterity, alertness, attention span, and ability to concentrate or special needs or limitations, requiring accommodations or adaptive support, and use of alternative skills; . . . [and] current mental health status.* . . . The diabetes educator . . . identifies and describes specific instructional strategies to be used, which reflect the needs, skills, learning style, and preferences of the client . . . [and] uses teaching materials appropriate to the learner's . . . learning style and abilities. [emphasis added]

This position statement provides guidance to diabetes educators regarding their ethical and legal responsibilities to persons with disabilities and promotes diabetes education for persons with disabilities that is equal in quality to that received by persons with no current disability.

Background and Definitions

Disability

In this position statement, disability is defined as a condition that substantially limits one or more major life activities. For a person with diabetes, major life activities include diabetes education and diabetes self-management activities. Examples of disabilities include, but are not limited to, amputation of all or part of a limb, blindness, chronic major depression, deafness, low vision, learning disabilities, manual neuropathy, and schizophrenia. This definition focuses on a functional limitation not on specific measurements of ability or on the source of the disability. For example, a person whose vision loss does

not meet criteria for legal blindness may nevertheless have substantially limited ability to measure insulin precisely using visual techniques. Decreased manual dexterity from any of several possible causes (neuropathy, arthritis, or traumatic injury) can limit someone's ability to handle small pills. Hearing loss may result from infection, trauma, or certain medications; all causes limit access to necessary information presented in oral lecture format. All of these conditions limit major life activities and are considered disabilities using the above definition.

Universal Design

Universal design is defined as the design of products, environments, and services to be effectively and efficiently used by persons with the wide range of abilities to the greatest extent possible, without adaptation or specialized design.³⁻⁵ A key concept is that a typical target population normally includes persons with a wide range of abilities and disabilities. In general, successful universal designs expand access for people with disabilities at a lower cost while also providing benefits for average users of a product or service. Universal design is conceptualized as a process, not an end point, in the spirit of continuous quality improvement. Because the concept is in early stages of development, no one knows yet what the greatest extent possible is for the use of any particular product, environment, or service. For DSME/T₂, important applications of universal design are to diabetes education programs in general and to consumer medical products. Diabetes education programs, like other education programs, can be designed to reach the largest number of learners possible without the need for special accommodations.^{6,7} Consumer medical devices (such as blood glucose meters and insulin pumps) can be designed to facilitate successful use by the largest number of persons possible.⁴

Disabilities and Diabetes

Disabilities are more prevalent among persons with diabetes than among those without diabetes.⁸ Some of these result from complications associated with diabetes, such as lower limb amputation or visual impairment from diabetic retinopathy. Some predate the diabetes diagnosis, such as developmental disabilities or congenital hearing loss. Some are not causally related to diabetes but, like diabetes, have increased incidence with aging, such as decreased dexterity from arthritis or visual loss from macular degeneration.

Disabilities can be visible and obvious, such as hemiparesis from stroke or total blindness. They can also be difficult to detect unless the observer knows to look for them, for example, decreased dexterity or gait irregularities. Or they may be indiscernible to most observers, such as learning disabilities or chronic fatigue from fibromyalgia. All of these disabilities can affect DSME/T.

Common disabling conditions among people with diabetes in the United States include arthritis that limits physical activity (52% of people with diabetes⁹), depression (twice as prevalent among people with diabetes as among those without¹⁰), hearing loss (twice as common among people with diabetes as among those without¹¹), peripheral neuropathy (30% of people with diabetes¹²) and visual impairment that limits ability to read regular print (approximately 19.7%).¹³

Numerous tools and techniques exist for self-management of diabetes by persons with disabilities. Furthermore, there are multiple organizations that can provide reliable information about the effects of specific disabilities.¹⁴

The Americans With Disabilities Act

The Americans With Disabilities Act of 1990 prohibits discrimination and explicitly requires professional offices of healthcare providers and hospitals to provide reasonable accommodations for persons with disabilities, to ensure that they have an equal opportunity to receive health care services.¹⁵

Reasonable accommodations for DSME/T can include, but are not limited to, locating services in a building that is accessible to wheelchairs; using an alternative method of communication, such as TTY or a sign language interpreter, for a person who is deaf; providing DSME/T take-home materials in audio format for persons who have dyslexia or low vision; teaching smaller amounts of material with more frequent visits for persons with short attention spans; and allowing service animals in conferences or offices.¹⁶

Role of the Diabetes Educator

Diabetes educators can play a key role in the care of individuals with disabilities and diabetes by providing DSME/T in a way that enables them to achieve similar behavioral change goals as persons with no current disability. Diabetes educators must plan DSME/T programs, as well as services for individuals with disabilities, so that both the process and the content of DSME/T are accessible and meaningful for persons with disabilities.

Diabetes educators should both employ and encourage use of universal design principles. They should design DSME/T programs to be accessible to most individuals without needing special adaptations for common disabilities.

Educating clients who have both diabetes and a disability requires communication among all healthcare team members and sharing of information about the effects of the disability on each individual and on each DSME plan.

Research is necessary to build evidence about best practices of DSME/T for persons with disabilities. Overall, very few studies have focused on DSME/T for persons with disabilities. Considering the large numbers of persons with disabilities who have diabetes, such research is necessary to provide effective DSME/T in typical populations.

Recommendations

- Provide DSME/T for persons with disabilities in a way that allows them to achieve similar behavior-change goals as persons with no current disability.

- Incorporate principles of universal design in the planning, implementation, follow-up, and evaluation of DSME/T programs so that individuals with the wide range of abilities and disabilities normally present in a population can be readily served in the usual program.⁷
- Include assessments of both obvious and hidden disabilities for each individual, using open-ended questions about the presence of any physical, mental, or emotional conditions that could affect the learning of diabetes self-management.
- When working with an individual who has a disability, assume responsibility for learning about both the effect of that disability on DSME/T and the tools and techniques available for self-management with that disability.^{14, 17}
- With permission from the patient, communicate with other rehabilitation professionals involved in the care of that patient, including but not limited to audiologists, occupational therapists, physical therapists, psychologists, social workers, or vision rehabilitation therapists.
- Make referrals to rehabilitation services as appropriate and to consumer disability organizations when these are available.¹⁵ Familiarity with available rehabilitation services and disability organizations in the area surrounding the DSME/T program will help the diabetes educator know when and how to make such referrals.
- Encourage manufacturers and publishers of both diabetes consumer technology and diabetes instructional materials to adopt universal design principles.
- Encourage researchers to build evidence for effective universal designs of DSME/T programs and also for specific tools and techniques to serve individuals with disabilities effectively.

Acknowledgements: Ann S. Williams, PhD, RN, CDE; Debra Sokol-McKay, MS, OTR, CDE, CVRT, CLVT, SCLV; Bonnie Bartos, PA-C, MHP, CDE; Michele Chynoweth, RD, CDE; Andrew A. Gerwitz Jr, RPh, CDE; Connie Kleinbeck, BSN, RN, CDE; Valerie A. Lawson, MS, RD, LDN; Sharon M. Shumaker, LISW; Dawn Sherr, RD, CDE

Criteria for rating evidence and grading recommendations*

Level-of- Study Design or Information Type

Evidence

1. Large randomized controlled trial (RCT); Multicenter trial; Large meta-analyses with quality rating
2. Randomized controlled trial that has some design or methodological flaws; Prospective cohort study; Meta-analyses of cohort study; Case-control study; Quasi-Experimental study (rigorous pre-post with a control group); Systematic review that is well designed
3. Methodologically flawed randomized controlled trial; Nonrandomized controlled trial; Observational study; Case series or case report; Review (note Cochrane reviews are systematic reviews that could qualify as Level 2 evidence)
4. Expert consensus; Expert opinion based on experience; Theory-driven conclusions; Unproven claims; Experience-based information; Opinion Piece

****This is not an exhaustive list – Reviewers will need to use their own judgment at times.***

References

1. American Association of Diabetes Educators. Code of Ethics. <http://www.diabeteseducator.org/About/governance/ethics.html>. Accessed May 19, 2011. (4)
2. American Association of Diabetes Educators. The scope of practice, standards of practice, and standards of professional performance for diabetes educators http://www.diabeteseducator.org/export/sites/aade/_resources/pdf/research/ScopeStandards_Final2_1_11.pdf. Accessed May 19, 2011. (4)
3. Center for Universal Design, North Carolina State University. About UD: Universal Design Principles. 2008. http://www.ncsu.edu/www/ncsu/design/sod5/cud/about_ud/udprinciples.htm. Accessed June 1, 2011. (4)
4. Wilcox SB. Applying universal design to medical devices. 2003. <http://dscience.com/pdf/DS-Applying-Universal-Design.pdf>. Accessed June 1, 2011. (4)
5. National Institute on Disability and Rehabilitation Research. Resources on accessible/universal design principles and performance measures. 2006. <http://www.erc-ami.org/ami/projects/d/2/udg/>. Accessed June 1, 2011. (4)
6. Center for Applied Special Technology. Universal Design for Learning Guidelines version 2.0. <http://www.udlcenter.org/aboutudl/udguidelines>. Accessed June 1, 2011. (4)
7. Williams A. Universal design in diabetes care: an idea whose time has come. *The Diabetes Educator*. 2009; 35(1):45-57. (4)
8. Centers for Disease Control and Prevention. Diabetes data & trends: health status and disability. <http://www.cdc.gov/ncbddd/disabilityandhealth/data.html> Accessed May 19, 2011. (1)
9. Centers for Disease Control and Prevention. Arthritis as a potential barrier to physical activity among adults with diabetes. *MMWR Weekly*. 2008;57:486-489. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5718a3.htm> Accessed June 1, 2011. (1)
10. Anderson RJ, Freedland KE, Clouse RE, Lustman PJ. The prevalence of comorbid depression in adults with diabetes. *Diabetes Care*. 2001;24:1069-1078.(2)
11. Bainbridge KE, Hoffman HJ, Cowie CC. Diabetes and hearing impairment in the United States. *Ann Intern Med*. 2008; 149:1-10. (1)
12. The Neuropathy Association. 2011. http://www.neuropathy.org/site/PageServer?pagename=About_Facts Accessed May 20, 2010. (4)
13. Centers for Disease Control and Prevention. Diabetes data &trends: visual impairment. <http://www.cdc.gov/diabetes/statistics/visual/fig2.htm> Accessed May 20, 2011. (1)
14. Bartos BJ, Cleary ME, Kleinbeck C, et al. Diabetes and disabilities: assistive tools, services, and information. *Diabetes Educ*. 2008;34(4):597-636. (4)
15. Americans With Disabilities Act of 1990. Public Law 101-336, 101st Congress. July 26, 1990. Washington, DC: Government Printing Office; 1990.
16. American Association of Diabetes Educators. Position statement: diabetes education for persons with disabilities. *Diabetes Educ*. 2002;28(6):916-921. (4)
17. *The Art and Science of Diabetes Self-Management*. Chicago, IL: American Association of Diabetes Educators; 2011:21-69. (4)