Person-First Practice: Treating Patients with Disabilities

In the increasingly competitive market for American health care dollars—particularly in the current climate of economic upheaval—it is essential that food and nutrition professionals ensure that their services are available, accessible, and appealing to every segment of the population. One such group of potential clients that you should be aware of is people with disabilities. According to the US Census Bureau, approximately one in five Americans has a disability (1). Therefore, food and nutrition professionals can reasonably expect a fair percentage of their patients to have a disability as well. In fact, since many of the conditions for which patients turn to registered dietitians (RDs) and dietetic technicians, registered (DTRs) for help, such as obesity or diabetes, can themselves result in disabilities, it is likely that more than one in five of your patients will have a disability. Not only do people with disabilities face the same risk of cancer, heart disease, and other illnesses as the general population—and therefore could benefit from the dietary advice of a nutrition expert—many people with disabilities “have problems managing their weight due to physical limitations which impose restriction on their movement . . . [and] are affected by the side effects of medications they take, particularly in terms of increased appetite and water retention” (2). People with disabilities are also often more susceptible to opportunistic infection, pain, and other ailments, which may be complicated or exacerbated by obesity (2). For these reasons, health care professionals are increasingly focusing on the role nutrition plays in prevention of complications associated with certain disabilities, so as a food and nutrition professional you must be prepared to meet the needs of this population by learning how to appropriately work with patients with disabilities, including preparation of the treatment environment, interaction with your client, and talking to and about a client with disabilities without using outdated or offensive terminology.

IDENTIFYING YOUR CLIENT’S DISABILITY

It is important to be aware that, although more than 50 million Americans have disabilities, only about 7 million people use a visible assistive device (3,4); and though you may be able to identify some other disabilities by sight, many of them will remain “invisible.” Invisible disabilities can take many forms, such as deafness, intellectual or developmental disability, or diseases with effects that are unseen but profound, and they are more common than you may think—more than 40 million people are limited in their daily activities by chronic illness, according to the National Institute of Nursing Research, and 75% of them are under the age of 65 years (5,6). Invisible disabilities advocate Wayne Connell explains that, “An invisible disability or chronic illness can be mental disorders such as bipolar disorder or depression, or it can be something like lupus, fibromyalgia, chronic fatigue, or Reflex Sympathetic Disorder” (5). Obviously, it would be impossible to spot a depressed person merely by sight, or to see that a client has rheumatoid arthritis or Crohn’s disease, but ignorance of an invisible disability is no excuse for unsympathetic treatment, so you will want to be mindful of these potential circumstances with every patient or client that you encounter. The next step is not to become a “disability detective,” attempting to deduce whether or not a client has a disability by interpreting body language or other subtle cues, but to simply remain aware of the possibility that a client may have a disability that could require changes in your typical treatment program. The best way to find out whether your client has a disability that will require special accommodations is simple: Ask. Not only do you avoid any potential awkwardness or confusion, you give the client the opportunity to describe the type of assistance he or she requires, opening a dialog that will give you a fuller understanding of the client’s disability and a better idea of how to treat him or her.

INTERACTING WITH YOUR CLIENT

It is also your responsibility, or that of your employer, to provide an accessible treatment environment. The Americans with Disabilities Act requires medical facilities and practitioners to “provide access for people with disabilities to health care services. The law requires reasonable accommodations—those that are readily achievable and that do not present an undue hardship on the facility. Practitioners and facilities need to learn about and provide specific accommodations for people with the full range of disabilities” (7). In addition to those accommodations mandated by law, a thoughtful practitioner will make or be ready to make any additional adjustments. This includes not only arranging the physical environment to the benefit of your patient, but reviewing and understanding guidelines for interacting with the patient depending on his or her disability. In all cases, it is important not to make any assumptions about the patient’s ability or desire for assistance. The patient is the “expert” on his or her own disability and knows what works best for him or her. Always let the patient determine the level of assistance he or she desires, be sure to ask before providing help, and never insist.

Considering your clients’ needs and preparing the physical environment for them is one aspect of proper etiquette for dealing with patients with disabilities. Perhaps more important, and potentially more difficult, is preparing yourself to speak to clients with disabili—

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ities without using inaccurate, dated, patronizing, or even offensive terminology. Mary J. Yerkes of the Illness-Disability-Healthcare-Caregiver Ministry Network, provides a general summary of the proper behavior and language to use when dealing with people with a variety of disabilities, including invisible disabilities, in the Figure. This convenient summary of what is and is not appropriate terminology or behavior when interacting with a person with a disability can serve as a quick, handy reference as well as a teaching tool.

After reviewing the basic etiquette for interacting with people with disabilities and understanding how disabilities can impact dietetics care, the next and most important step in the communication process is learning to address the individual rather than the disability. This is best accomplished through the use of a technique known as person-first language. The words we use carry a greater meaning than just the literal meaning of their dictionary definitions because of the connotations associated with them, and those connotations can color our perceptions (8). Person-first language takes these factors into account when talking to or about people with disabilities by placing emphasis on the person rather than the disability.
but a person is not and should not be defined by his or her disability (9).

People with disabilities, just like those without disabilities, are mothers and fathers, husbands and wives, students, professionals, volunteers, athletes, and artists, among other things, and their disabilities are simply one of the many things that combine to form a whole that is greater than the sum of its parts—and certainly far greater than any disability. Focusing solely on a person’s disability is no different than emphasizing any other single characteristic, and it devalues the individual (10). Calling someone a female doctor, an African-American judge, or a Latino architect calls undue attention to a characteristic that has no bearing on that person’s performance, and implies a dif-

Figure. (Continued) Disabilities etiquette 101. Reprinted with permission from the December 2008 Associations Now, ASAE & The Center, Washington, DC. Text used with permission from Mary J. Yerkes, a freelance writer and disabilities advocate who lives with rheumatoid arthritis.
ference from the standard definition of his or her role. This focus on difference typically carries a negative connotation and perpetuates offensive negative stereotypes in both the mind of the speaker and those listening. As a food and nutrition professional, it is essential that you avoid these pitfalls when interacting with clients with disabilities.

Exceptions to the Rule
Although person-first language is nearly always appropriate, there are people with disabilities who prefer not to use it. Some people who are deaf or hard of hearing and some people with autism prefer the terms “deaf person” and “autistic person,” respectively. They view deafness or autism as an essential part of their identity and identify themselves as part of the deaf or autistic community. In fact, some people do not consider these conditions disabilities at all, preferring to see them only as traits that differ from those of people without hearing impairment or autism (11,12). In treating a patient who is deaf or has autism, ask the patient which terminology he or she prefers.

EXPERT OPINIONS
Familiarizing yourself with the basics of disabilities etiquette is an important first step in dealing with clients with disabilities, but it’s essential to understand how disabilities can impact dietetic care. Patricia Henry, MEd, RD, is chair of ADA’s Dietetics in Physical Medicine and Rehabilitation Dietetic Practice Group as well as a nutrition coordinator and certified diabetes educator at Tomball Regional Hospital in Texas; Joan Guthrie Medlen, RD, is the founding editor of the Disability Solutions newsletter, author of The Down Syndrome Nutrition Handbook, and the mother of a son who has Down syndrome, autism, and celiac disease. They offer their expertise in dealing with people with both visible and invisible disabilities.

How can proper disabilities etiquette be incorporated into dietetics practice?

Joan Guthrie Medlen: Health literacy guidelines are very useful in coaching dietitians and other health care providers in effective and respectful communication styles. At the very least, health care professionals must be diligent in communicating in a respectful manner that is understandable to the person we’re working with. For some, this requires little modification. For others, it requires modification of vocabulary, speed of speech, and even the use of visual tools. Check back frequently to be sure the person you are working with understood and knows how to take action.

Patricia Henry: You need to make sure your physical environment can accommodate the client. If someone comes in who is extremely obese, you need to make sure your furniture can accommodate his or her size. Your office will need to be large enough to accommodate a wheelchair and another chair if the client brings someone with him or her. You should also know where the wheelchair-accessible restrooms are in case the client asks. If you can’t accommodate the client in your office, you need to have an alternate site and be sure it is confidential.

If your client is visually impaired, you should provide large print-materials. If the client is hearing impaired, you should provide things he or she can see and not have to hear. If the client has an amputation, you may want to know what facilities he or she has at home to accommodate cooking (eg, lower counters, easily accessible sinks). You need to be more detail-oriented, as not every restaurant may be accessible, so the client may go to a select few that are. If the client has to depend on someone to take him or her grocery shopping, this may limit what foods he or she has available.

Medlen: Give the gift of time. Regardless of disability, many people who have disabilities—physical or intellectual—need more time. Schedule generously for questions, for the extra time it takes to travel to and from your office, for the extra time it takes to process information, and so on.

What is the most important thing for food and nutrition professionals to keep in mind when treating patients with disabilities?

Henry: They are people too. I let them guide me in what I can do for them. My first question is, “What brings you here today and what can I do for you?” My last question is “Is there anything else I can do for you?” If needed, I will ask the client’s per-
mission to call the Social Services department while he or she is here in order to obtain any services he or she needs. I always let the client make the first move. If the client has a short attention span, I ask him or her what he or she feels is the most important thing he or she needs to know, and I focus on that.

Medlen: Person-centered care. Focus on the individual, not the disability, and you will be a success. If you think about it, that’s what we suggest for all our clients. Use the same processes (eg, motivational interviewing, nutrition coaching) as your tools. Your clients will tell you all you need to know. Trust them. Focus on strengths, gifts, and capacities. Not disability.

Medlen and Laura Foresta, RD, a private practice dietitian with LAF Nutrition and Wellness LLC who has experience running a weight management program for developmentally disabled adults, also offered practical advice specific to patients with intellectual and developmental disabilities:

• Lecturing this population does not work well. They often have difficulty following and get bored. Nutrition education that allows clients to engage in an activity is much better received and the clients are more likely to remember the lesson.

• When working with a person who has an intellectual or developmental disability, do not assume he or she is not his or her own guardian. Speak directly to that person in a way they can understand and wait for them to make decisions or for them to ask their support person for assistance.

• Use age-appropriate tone and language. Educational materials with pictures often work well, but most picture-oriented educational materials are geared toward children and should not be used. For example, using the children’s, MyPyramid is not appropriate for an adult with an intellectual or developmental disability or someone who has trouble speaking. Developmentally disabled adults know they are different, and know they are not children, so giving them children’s materials is insulting.

• Follow the basic rules for plain or clear language in your communication style. The person who is accompanying him or her is secondary to the conversation and may or may not know the person well. When in doubt, make a follow-up call or send written information with the person that includes your phone number for questions. Make sure they know to call you or to have their family member or support person call you with questions.

• Do not assume a person with intellectual or developmental disability has adequate funding. Ask if they need assistance getting food the same way you would anyone else. Many people living in the community who have intellectual or developmental disability are limited to a set income by Supplemental Security Income so they can also have health insurance (Medicaid). Be sensitive to that when making suggestions regarding foods and shopping strategies.

• Offer choice, especially for people living in group settings. Find ways to help the support staff build in individual choices. The budget may be tight, but many food-related behaviors for people with intellectual and developmental disabilities living in group situations are the result of not being in charge of their lives or of their food.

• Remember that they may have had very bad experiences with people in the medical profession over the course of decades. As with any person you are working with, trust is not freely given; it is earned. Show respect, interest, and desire to work for them and with them, and you will earn their trust. Do not make a promise you will not keep.

• Teach, don’t test. People with intellectual or developmental disabilities are too often tested to see what they know. Just as you would with anyone, find out what they want to know and teach them.

• For more ideas of ways to modify your work for understandability, keep the concepts of universal design in mind (see www.cast.org), both for the physical environment and for modification in instruction and communication.

While some of the etiquette, terminology, and techniques associated with working with people with disabilities may be new to you, in the end, the most important thing to remember about people with disabili-

References