Educating Consumers About Assistive Technology

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The concept of independent living by persons with disabilities emerged about 35 years ago (Frieden & Cole, 1985). Its principal tenet is that a person with a disability should have the same degree of control over all facets of life as anyone else, "including managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self determination and the minimization of physical and psychological dependence on others" (Frieden & Cole, 1985, p. 735). The similarity to occupational therapy treatment goals is striking, as pointed out in the American Occupational Therapy Association's (AOTA) "Draft Statement: The Role of Occupational Therapy in the Independent Living Movement" (Bowen, Jones, & Shriver, 1992). But, though our treatment goals may be formulated around the notion of independence, incorporating this meaning of independence into the methods of evaluation, treatment planning, and treatment within our present service provision systems can be challenging. Because of current legislative and social changes relating to assistive technology, the provision of assistive technology services is a good example of how to meet this challenge.

According to Frieden and Cole (1985), the goal of the independent living movement has been to "overcome the barriers to a higher quality of life," assuming that, "given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals may actively participate in all aspects of society" (p. 735). Borrowing from the concurrent emphasis on consumerism in society, we could approach the provision of assistive technology goods and services by examining how we can empower persons with disabilities to seek out and acquire the technology they need independently. This approach is addressed within the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Public Law 100-407) (Tech Act), the first piece of federal legislation to use the phrase "consumer responsive" in defining how services should be provided.

When we think about consumerism, we usually picture the person who, when buying a washing machine, a car, or a stereo system, goes to the public library, finds the past years' issues of Consumer Reports, and compares features, styles, prices, and performance evaluations of several different brands. The person shops around, weighs alternatives, and investigates financing. She or he listens to the product, test-drives it, or asks for a demonstration of it. After talking to different salespeople, experts in the field, and other consumers, the person makes a decision and buys the product. If the product has problems, the buyer calls the retailer and, if necessary, the manufacturer, the Better Business Bureau, and eventually the state Attorney General.

This process differs remarkably from the way most people acquire assistive technology or at least from the way they get their first wheelchair, walker, or bath seat. There are many different reasons for this discrepancy, including the setting in which it is done; the attitudes and expectations of the professionals, the consumers, and the salespeople; and the manner in which equipment is paid for. The point is that everyone plays a role in perpetuating this model, and everyone has the potential to introduce change.

If we return to the independent living movement's assumptions about how to assure the full participation of persons with disabilities in all aspects of society, we can imagine a method of providing assistive technology goods and services that fits our picture of the consumer more closely. The informed and involved consumer seeks out pertinent information and is skilled in evaluating products. She or he has access to the sales and information environments and knows where to go for additional support.

Some of the consumers of our services may have difficulty fulfilling some of their responsibilities within this consumer model because of the nature of their disabilities, but the larger part of...
the problem is with our own attitudes as service providers and with the nature of the system under which we operate. By placing the steps of the assistive technology acquisition process within the framework outlined by Frieden and Cole, the therapist and the consumer can identify which parts the consumer will need training, support, or assistance with and which parts the consumer already has the skills to complete independently. The therapist must then be comfortable sharing or passing along responsibilities, or must risk fostering continued dependence.

Pertinent Information and Skills

When evaluating equipment needs, we all tend to rule out certain solutions and direct consumers toward others. We base this tendency on our years of clinical experience and can easily justify why one solution is not worth considering. We must be careful, however, that when doing so, we are not denying consumers access to information. Involved them more in the evaluation, brainstorming, and researching process can help ensure this, as can listening to their needs and concerns and taking the time to answer all their questions and direct them toward other resources. Consumers can be referred to databases and indexes such as ABLEDATA, local and state centers funded by the Tech Act, or national rehabilitation engineering programs with information services. Although there is no comprehensive source like Consumer Reports for comparing or evaluating all assistive devices, there are now international testing standards that manufacturers can use for comparing and reporting the performance of manual and powered wheelchairs. There is also a small body of research from federally funded programs reporting on the functional outcomes or effectiveness of various products and devices. Therapists working in assistive technology centers should not only keep up with these developments, but should make the information accessible to consumers as a matter of course.

Some independent living centers, clinical facilities, and manufacturers offer consumer workshops, booklets, and videotapes on how to operate, maintain, and repair equipment. Learning skills in self-advocacy must also be addressed. Consumers need to be involved in price and funding decisions and must be aware of their rights and responsibilities as consumers. Many independent living centers and rehabilitation facilities provide training and publications in these areas as well (Arnowitt-Reid, 1986; Waldron, 1982).

Accessible Environments

Consumers need more than just physical access to a place where evaluations are held; they also need access to products for demonstration and trial use. If we expect them to make decisions about equipment that they will have to use for 3 to 5 years before it can be replaced, they should be able to see it, handle it, sit in it, and try it out within their homes whenever possible. They also need direct access to sales and manufacturing personnel throughout the selection process. Too many therapists rely on one specific vendor or manufacturer and deny consumers the right to choose their own. This greatly disempowers consumers, because it gives the vendors the impression that they are competing for the therapist's business, rather than for the individual consumer's business. They may then respond more quickly to calls from the therapist, putting the consumer on the back burner and perpetuating the consumer's dependence on the therapist. Direct access to vendors and manufacturers is also important for feedback and design input and can positively influence the development of new products that truly reflect the market need.

Appropriate Supportive Services

Even with the changes described above, some consumers will continue to need assistance in acquiring the appropriate technology. They may need help in identifying and evaluating their own needs, in making decisions about products, or in finding financial resources to pay for equipment. If we keep a consumer orientation in mind, we can provide these services without reducing their control of the outcome or relieving them of their own responsibilities in the process. We can define our role as a consultant, hired by consumers for counseling, education, and provision of the resources and tools they need to continue the process on their own, much as we hire consultants for financial and legal advice.

The key in providing services within the independent living or consumer education model is focusing more on the similarities than on the differences between therapists and consumers. Jan Levine's advice on working with persons with disabilities may illuminate some of what goes wrong, or what keeps people from achieving the goal of independence, despite the best of intentions and therapy.

References


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