Technology and people with disabilities: ethical considerations.

By: Leandra A. Bedini

Article:

Thrusts of the political and social movements for equality for people with disabilities in the work place and in the community are slowly being realized. Issues of equity, independence, and normalization have been brought to the forefront of social consciousness through legislation such as the Americans with Disabilities Act of 1990, advances in technological applications, and social awareness of all people. Although a lot of work remains to be done, people with disabilities are becoming more visible in work, community, and recreation environments.

For people with disabilities, growth and availability of technology has had a great impact on opportunities for participation and on enhancing elements of independent living (cf. Cavalier, 1987). Technological adaptations have made it possible for persons with disabilities to participate in previously inaccessible work and leisure opportunities. The purpose of this article, however, is to present and examine ethical issues dealing with attitudes and policies that surround the application of technology for people with disabilities. Is it possible that the introduction of these technological advances is actually contradictory to the independent living movement? Are caregivers and professionals who work with people with disabilities running the risk of negating independence, normality, and least restrictive environments by blindly promoting technology? Despite the many rehabilitation successes attributable to technology, these and other ethical considerations must be explored to truly approach equity and normality for people with disabilities.

It is not the intention of this article to resolve these controversial issues. Rather, this article will present and discuss four major ethical issues which may be potential problems in the application of technology for people with disabilities: (a) inappropriate priorities, (b) functional/limitations model, (c) elitism, and (d) dependence. Therefore, these discussions should be viewed as a starting point for recreation and leisure professionals to examine and explore their roles in the application of technology for people with disabilities.

Inappropriate Priorities

Cavalier (1987) cautioned that particular attitudes by society can have "dangerous implications of technical applications" (p.133). Two scenarios exist whereby caregivers or educators might neglect needs of the consumer by placing inappropriate priorities on the application of technology. Because of the novelty of some equipment, it is easy to focus on the actual technology rather than on the individual consumer's needs. Similarly, sometimes, due to lack of knowledge or need for convenience, service providers may address their own needs and values rather than those of consumers.

Primary Focus on Technology

Focusing on technology alone can result from several circumstances. First, some schools or caregivers experience competitive pressure to have the most powerful technology available (Cavalier, 1987). Although this is usually initiated by well intended caregivers, high level technology is not always the most appropriate technology for people with disabilities. Sometimes, low technological options should be chosen over high tech options simply because they better meet the needs of the individual (Cavalier, 1987; McMurray, 1987; Parette & Van Biervliet, 1991). As McMurray noted, society has a "propensity for gadgetry" which can interfere with

the assumption of a normal lifestyle for people with disabilities. In some cases the newest high technological options are employed even before the needs of the consumer are determined (Cavalier, 1987; Garner & Campbell, 1987).

Additionally, expecting the person with a disability to adapt to the device rather than adapting the device to the individual is a common problem which can have negative consequences for the user. As Cavalier (1987) noted, "In such cases, a portion of the user's individuality is traded to fit the system rather than adapting the system to meet the particular individual need" (p. 133). It is important to retain focus on the educational or functional skills of the individual rather than on the novelty or attractiveness of the device in question.

Dignity of Choice
Several considerations are important to avoid focusing on the technology rather than the individual. First, it is important to realize that technological devices need not do everything (Garner & Campbell, 1987; Zola, 1982). Individuals with disabling conditions might opt to solve their own problems without adaptations. Parette and Van Biervliet (1991) described the concept as dignity of choice, stating that the consumer should be allowed to participate in decisions made about what technology to employ and how best to meet his or her own needs. As service providers we must not forget that people with disabilities are people first. Zola (1982) proposed the possibility that one's "psychosocial" body might reject parts that he or she feels are alien (i.e., using adaptive devices), much the way a body might reject a transplant. Emotionally, it might be better and more constructive for an individual to function without the use of a technological device. As Parette and Van Biervliet (1991) stated, the use of technology should help [the person] feel more normal. It is the judgment of the person with the disability, not the service provider that counts.

Caring and Technology
Closely related to dignity of choice is the issue of care. Zola (1982) cautioned that caring is not a technical task. He proposed that care requires personal interaction. Although the advancement of technological equipment such as life support devices was rooted in caring and a desire to return patients to healthy and productive lives, technology was never intended to prolong death (Schemmer, 1988). Current emphasis on technology, however, has redirected the focus of health care from the patient as a person to the "technically definable aspects of the person" (Schemmer, 1988, p. 38). One must be cautious not to over-technicalize or replace the human element and subsequently compromise the individual (McMurray, 1987; Zola, 1982). The use of technology can cause the loss of meaningful contact which in turn robs people of their dignity (Kitson, 1988; Schemmer, 1988). One must be able to use equipment to facilitate living and not surrender the benefits of human interaction and social bonds as a result.

Imposing Caregiver Needs and Values
A second scenario in which priorities can be in appropriate is when the researcher's or caregiver's needs or values take precedence over the consumer's needs (Pfrommer, 1984). This can result from several circumstances. First, it is difficult to keep up with all the technological advances occurring in society today. Once a technicque or device is mastered, it is likely another will be created to replace it. This becomes a problem when neither the system nor the trainer can upgrade due to lack of money, training, or desire. Thus, it becomes possible that an individual gets only the technology that the trainer knows how to use (Garner & Campbell, 1987; Parette & Van Biervliet, 1991; Pfrommer, 1984).

Another example of caregivers placing their needs over those of the clients is when technology becomes a pacifier for the client (Parette & Van Biervliet, 1991). For example, computers have programs and devices that can keep an individual entertained for extended periods of time. If the purpose of the activity is diversion and enjoyment, there is no criticism. There are situations, however, in which persons with disabilities, especially children with disabilities or individuals with severe disabilities, are placed in front of a machine to keep them quiet or get them out of the way. The ethical violations in this case are obvious, although they can be easily rationalized. It is important to keep the needs and well being of the consumer in the forefront and evaluate the

technological device to determine if it advances the long term needs and interests of the individual with a disability.

A third way that caregivers' needs take priority over those of the consumer is when the service providers attempt to meet their own needs to care and nurture by ascribing to the helper/helpee roles. This pattern of behavior encourages an unequal relationship between the service provider and the consumer by assuming the role of protector, one who knows what is best. Through this patronizing behavior, the service provider views the person with the disability as needy and dependent. Although not blatant or intentional, this attitude encourages the service provider to assume needs in the consumer that perhaps do not exist. Cavalier (1987) asked an important question related to this phenomenon, "Do all broken people want to be fixed"? Service providers cannot assume that since these individuals have disabilities, they would benefit from these devices.

Zola (1982) also suggested that consumers might not be as proud or grateful to use these devices as the service providers may think. It is important that service providers in schools, communities, and leisure arenas do not subscribe to the charity role whereby people with disabilities are expected to be grateful for any technology they get regardless of its appropriateness (Parette & Van Biervliet, 1991).

Functional/Limitation Model
The second major ethical issue concerning the application of technology to people with disabilities is an attitude that prevails in relation to any type of dysfunction or disability. Hahn (1991) proposed that the often used functional/limitation model of rehabilitation addresses the dysfunctional element of the individual with the assumption that some ability is lacking. Thus, focus is placed on the disability rather than on the ability of the individual. Additionally, he stated that this model makes the incorrect assumption that people with disabilities wish to eliminate their disability. Hahn challenged this proposition by suggesting that some individuals with disabilities may find dignity and identity within their disability. Thus, society must ask itself if it has the right to judge which behaviors are appropriate and which are not.

Pfrommer (1984) identified that labels of sick or disabled are encouraged by some distributors of technological devices. Cavalier (1987) and Parette and Van Biervliet (1991) cautioned against viewing people with disabilities as needing repair, thereby reducing a person to the sum of his or her parts. Cavalier (1987) called this attitude one of disabling images of the person with a disability. Some use of technological devices may actually increase the visibility of the inability. In some cases, when an individual uses a device, attention is brought to the deficit that the device is replacing. The individual might be seen in terms of the things that he or she cannot do rather than those he or she can. As a result, the individual as a person with emotions and feelings may be ignored. This awareness, brought on by the existence of the technological device, can create negative labels separating the individual with the disability rather than integrating him or her into the environment. This label, in turn, clearly compromises the ability of individuals with disabilities to experience normalized living and function in a least restrictive environment. Therefore, the question must be asked, Is the independence gained from technical assistance worth increased visibility of the disability? (Cavalier, 1987).

Not all technology is detrimental to automony and independence, however. Empowerment of the individual with a disability is an essential goal of rehabilitation. Although technology can indirectly disempower people, there are endless examples of how it is used to empower them. Comprehensive rehabilitation programs are necessary to focus on the individual as a whole, however. Several models addressing empowerment do exist in rehabilitation. For example, the ecological model (Howe-Murphy & Charboneau, 1987) focuses on the resources of the person, as well as his or her environment, rather than on the disability. Adopting a philosophy of rehabilitation that departs from eliminating deficits and moves toward encouraging abilities and considering all support networks can help professionals and consumers make important decisions regarding costs and benefits of technical assistance.

Elitism

Basically, there are two ways in which people with disabilities can experience discrimination or elitism regarding technological devices. First, assistive devices typically are very expensive. This is due partly to liability insurance expenses, as well as to the fact that devices are not produced in large enough quantities to be marketed at reasonable costs. Similarly, often these items must be custom made. According to Pfrommer (1984), manufacturers who obtain financial support from federal projects for research could pass savings onto the customer. This rarely occurs in practice, however. According to PL 101-336, the Americans with Disabilities Act of 1990, section 2 (a) (6), census data and polls have identified people with disabilities as a group that is inferior and disadvantaged economically. As a result, many individuals with disabilities cannot afford the excessive costs of technological devices.

Closely related to the financial ability of people with disabilities is whether it is fair to teach those individuals who have no access to these devices at home or in the work place to use devices in schools or training centers. Many schools are attempting to integrate technology in the instructional programs in the classroom. This idea is beneficial for educational purposes within the school; however, many of the children are not able to maintain these items in the home (Parette & Van Biervliet, 1991). Law (cited in Hansen & Perlman, 1989) raised concern regarding employers' lack of understanding and willingness to employ technology in the work place to facilitate people with disabilities. Although people with disabilities may benefit from training and become more independent, that independence is compromised upon leaving the classroom or training center. Ethically, is it fair to teach someone skills with equipment to which they will not have access outside of school?

McMurray (1987) suggested that individuals with disabilities who subscribe to technological devices to overcome obstacles may actually be creating a stereotype for those who cannot afford the devices and as a result go unnoticed. Those who can afford these devices in the home are the elite few and are separated from the others based solely on ability to buy. These priorities need to be examined and a continuum of service needs to be established outside of the schools and training centers to assure continuity of independent living for all individuals. For example, community recreation programs should consider acquiring and maintaining selected equipment that could be available for use to enhance leisure of individuals with disabilities. Also, it is important for leisure service professionals to act as advocates to encourage employers to make reasonable accommodations for hiring and maintaining people with disabilities in the work place in keeping with the Americans with Disabilities Actregulations. Without some investment from the community, little transferability exists for the abilities people with disabilities attain in training.

A second type of elitism is discrimination based on ability. McMurray (1987) discussed the image of physical prowess in that while it is important to promote the concept of competence for independent living, easily done with technological devices, service providers must be cautious to not exclude individuals who have lesser talents. It seems possible that with use of technology, those who can use it might actually set themselves apart from those who cannot. Thus, a new inferior category is created within people with disabilities based on technology-borne competence alone. It is not the intention of this article to suggest that individuals should go without equipment that can make them more functional in their society, but it does caution that the inappropriate use or overuse of technological devices might present unexpected consequences compromising normalcy for individuals with disabilities.

Dependence

The independent living movement of the 1970s and 1980s stressed least restrictive environment and independent functioning. In many ways technology has aided in that goal. Zola (1982), however, suggested that technology can do too much for people with disabilities. He stated, that technology can "rob us of our integrity by making us feel useless" (p. 395-6). Zola also demonstrated concern for what he calls internal attachment which in essence causes dependence on a machine. Parette and Van Biervliet (1991) offered a hypothetical example where in the extended use of a wheelchair might keep an individual from learning independent ambulation. Although the choice depends on several factors, the potential level of dependence should be weighed to determine the ultimate benefit for the individual in question.

Cavalier (1987) raised the question, "is dependence on assistive technology any different from dependence on people?" Service providers, as well as consumers need to assess the conceptual consequences and values of dependence and determine if technology does, indeed, encourage or discourage independent functioning. Similarly, Gloade (1987) cautioned that becoming too dependent on a technological device should be contraindicated since technology is changing so quickly. Cawley and Murdock (1987) noted that problems are possible in computer applications because the development of appropriate software is greatly lagging behind that of computer hardware.

Shannon (1984) suggested that humanity has tried to be free from domination of nature and now finds itself dependent on a creature of humanity's own making (p. 133). This issue is particularly important for those on life support equipment. According to Shannon (1984), the dilemma regarding quality of life is presented by the technological imperative that states if we can do it, we should. Technological advances have not only saved lives but also prolonged them. Schemmer (1988) asked, however, if technology prolongs life unnaturally? While we can ask what right we have to terminate life that technology can prolong, the issue of beneficience, or what is best for the patient, arises. These specific questions cannot be answered in this short discussion; however, it is important to raise them for consideration. Has society's love affair with technology gone too far?

Conclusion

The purpose of this article was to raise several ethical issues surrounding the use of technology with people with disabilities. Cavalier (1987) stressed that there are many responsibilities that accompany technology and its applications. As Garner and Campbell (1987) cautioned, "technology without values is dangerous" (p. 129). It is essential, therefore, for the rehabilitative process to retain perspective on the integrity of service and the true meaning and value of independent living. Technology must be guided by values and philosophy (Parette & Van Biervliet, 1991) focusing on choice and dignity.

McMurray (1987) stated that we should not use technology to compensate for loss of a function. To the contrary, she proposed that we encourage "...a human response to another human being, recognizing that person's right to exist with a choice as to how that existence can be made comparable to the lives of others" (p. 159). As leisure service providers, therefore, we must be guided by questions about the meaning of normalized lifestyle, independence, and autonomous existence. Then we must ask if the application of a particular device is indeed in keeping with this philosophy and goal.

Selected References

Cavalier, A. (1987). The application of technology in the classroom and work place: Unvoiced premises and ethical issues. In A. Gartner & T. Joe (Eds.), Images of the Disabled, Disabling Images (pp. 129-142). New York: Praeger.

Cawley, J.F., & Murdock, J.Y. (1987). Technology and students with handicaps. Contemporary Educational Psychology, 12, 200-211.

Garner, J.B., & Campbell, P.H. (1987). Technology for persons with severe disabilities: Practical and ethical considerations. Journal of Special Education, 21 (3), 122-132.

Gloade, F. (1987). Empowerment of the physically disabled through the use of technology. Rehabilitation Research Review, 13 (2), 29-34.

Hahn, H. (1991). Theories and values. Ethics and contrasting perspectives on disability. In R. P. Marinelli & A.E. Dell Orto (Eds.), The Psychological and Social Impact of Disability (3rd ed) (pp. 18-22). New York: Springer Publishing Company.

Hansen, C.E., & Perlman, L.G. (1989). Technology: A vital tool for people with disabilities. Journal of Rehabilitation, 55, 18-21.

Howe-Murphy, R., & Charboneau, B. (1987). Therapeutic recreation intervention: An ecological perspective. Englewood Cliffs, NJ: Prentice Hall.

Kitson, A. (1988). On the concept of nursing care. In G. Fairbairn & S. Fairbairn (Eds.), Ethical issues in caring (pp. 21-31). Brookfield, VT: Gower Publishers.

McMurray, G.L. (1987). Easing everyday living: Technology for the physically disabled. In A. Gartner & T. Joe (Eds.), Images of the Disabled, Disabling Images (pp. 143-160). New York: Praeger.

Parette, H.P., & Van Biervliet, A. (1991). School age children with disabilities: Technology implications for counselors. Elementary School Guidance and Counseling, 25 (3), 183-193.

Pfrommer, M.C. (1984). Utilization of technology: Consumer perspective. In Discovery '84: Technology for disabled persons. Chicago, IL.

Public Law 101-336. The Americans with Disabilities Act, 1990. Findings and purposes, section 2 (a) (6), 42 USC 12101.

Schemmer, K.E. (1988). Between life and death: The life support dilemma. Wheaton, IL: Victor Books.

Shannon, T.A. (1984). Dying in a technological age. New York: Edwin Melen Press.

Zola, I.K. (1982). Social and cultural disincentives to independent living. Archives of Physical Medical Rehabilitation, 63, 394-397.