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Conclusions From Part One

It is not the hand but the understanding of a **man** that may be said to write.

—*Miguel de Cervantes*

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Conclusions From Part One

The purpose of Part One is to provide background information on disabilities and handicaps that places later material on technologies and on resource allocation in perspective. The need for technology and for the allocation of resources to develop and distribute them is, after all, derived directly from the existence of disabilities and handicaps. The numbers and specific types of limitations on people's functioning are, or should be, a principal source of guidance for Federal and other programs that develop and diffuse technologies and that expend funds for the use of technologies.

DEFINITIONS

The three-tiered definition in chapter 2 of impairments, disabilities, and handicaps has significant implications for rehabilitation approaches based on the application of technology. Because it is the most objectively diagnosable condition of the three, and because it is based on a physical or mental loss or deficiency, an impairment is the condition for which medical care is the most crucial and appropriate. Medical or surgical intervention is usually the first form of intervention applied in order to eliminate or reduce the impairment, to keep it from becoming a disability or to keep the disability to a minimum.

As long as the impairment exists and is not fully compensated for, however, a disability will also exist. With disabilities, the *role of medical care is still important, but it will normally be supplemented by other interventions.* Some of these will be quite closely related to medical care, such as training in the use of braces. Examples of other types of services that become important include attendant care, special education services, modified automobiles, environmental control systems, and communications devices.

The objective of any technological application is to eliminate, reduce, or bypass functional limitations of the individual. When limitations cannot be eliminated, a disability remains but it may be prevented from handicapping the individual. A handicap, as defined in chapter 2, is the result of interaction between a disability and the social and physical environments of the disabled person. *A disability may change the way one accomplishes a task or reduce one's ability to do it at a certain level, but a handicap may prevent the person from doing the task at all or at an acceptable level (to* the person). For example, a person who uses a communication device that produces artificial speech will speak in a different way from nondisabled people, and that person may not be able to speak as quickly or as expressively as is "typical. " The person may become handicapped by that disability in combination with social expectations for conversational style and rate.

A person's disability may change over time. For example, physical and mental conditions improve and deteriorate. The aging process carries with it a gradual lessening of some functional abilities, such as sight and hearing. New technologies are developed or are acquired by the disabled person, and these may change or influence abilities and disabilities. Handicaps, too, can change. In fact, *the nature of handicaps implies that they* can *change daily or even hourly, depending on changes in the disability -environmental interaction.* When a wheelchair fits through a doorway and into an elevator, the disabled person has access and is not handicapped in relation to that functional ability. An hour later, in the next building, a doorway may create a handicap.

Having noted these properties of disabilities and handicaps, OTA finds that accurate terminology would involve using the phrases "a person with a limitation on the ability to perform one or more functional tasks because of an underlying condition, " or "a person with a disability in one or more

functions who is, in a particular situation, limited in the ability to accomplish certain tasks. " However, the terms "disabled person" and "handicapped person" are useful as a shorthand. In this report, therefore, the terms disabled or handicapped person or individual should be read as implying the longer phrases.

The properties of disabilities and handicaps also lead to several conclusions relating to Federal policies. *Even though the role of medical care and medical specialists may lessen in the progression from impairments to disabilities to handicaps, Federal policies are still primarily oriented to medical solutions.* As will be covered in chapter 9, a physician's prescription is required for many devices and services not of a strictly medical nature. Reimbursement under Federal health insurance programs is not permitted to rehabilitation engineers. The criterion for inclusion in reimbursement appears to be less concerned with effect on health or functioning than it does with affiliation with a medical field.

Similarly, the properties of disabilities and handicaps as defined here imply that the person with those conditions could play a substantial role in identifying needs for technologies, deciding to acquire or use technologies, applying them, and assessing their worth. This is not to say that the disabled individual is the best judge of all aspects of technology use. However, OTA finds that *often, more attention has been paid to the disability than to the person with the disability.* Thus,

many opportunities for more informed and appropriate use of technologies may have been missed. A source of expertise has been substantially overlooked. It may be that many researchers are more interested in what they can do for disabled people than in what ways they can assist disabled people in doing things for themselves, or that many program administrators are more interested in what their programs can do directly than in what disabled people can do on their own, given opportunity and some level of resources. These possibilities cannot be investigated and resolved fully, but the evidence available to OTA indicates that they have some basis in fact.

Although the situation is changing somewhat, many Federal policies and programs are oriented to thinking of disability in terms of categories of disease or diagnosis. This orientation of programs is reinforced by the categorical organization of most advocacy groups and other consumer groups. *One partial result of viewing disability in categorical instead of broader functional terms is the narrow focus and lack of coordination that characterizes Federal* efforts.

The categorical orientation may also result in less than an adequate share of attention and resources being devoted to changing the environment within which disabled people function, or to changing the way in which the disabled person interacts with the social and physical environments.

NUMBERS

OTA finds that "numbers" are a critical problem area. Aside from their use in debates about the national costs or missed opportunities due to disability, counts of the *total* number of disabled people in the country are deceptive, ambiguous, and, for most policy purposes, unnecessary. *The biggest need for the appropriate use of technology and for the planning of governmental programs is valid, reliable data on the numbers of people with specific forms of functional limitations and on the demographic characteristics of the people.* Such data do not exist in sufficient amounts to greatly improve policymaking and the use of tech-

nologies. Methodological weaknesses contribute to the poor state of information, *but* increased attention and funds for the collection of data relevant to decisionmakers could be of tremendous help. *A concerted* effort *to improve data collection methods and systems is needed before large sums of money should be spent on actual collection. This* effort *must include substantial participation by people with disabilities.*

The above discussion should be seen in light of the fact that existing statistics, especially those on impairments or categorical conditions, usual-

ly were not designed to meet the now apparent needs of policy makers and others. In addition, data on impairments and other categorical information may still be needed for certain purposes (e.g., planning the allocation of specific prevention services).

The goal of most public and private nonprofit organizations should be to make their efforts less and less necessary over time. They should work toward the reduction of handicapping forces— e.g., physical and attitudinal barriers to mobility, transportation, employment, education, and training. This perspective on the part of organizations should then lead them to identify, *generate, and disseminate data not only* for *their*

own immediate, program-related uses but also for the purposes of *reducing barriers and involving others in the effort, such as private firms.* This implies, for example, that the Social Security Administration may want to identify areas, and collect data about them, where the need for income maintenance and health care resources could be reduced due to the lessening of handicapping elements. Similarly, the National Institute of Handicapped Research could decide to include, to a much greater extent than at present, the data needs of manufacturers and marketers of disability-related products in the agency's own designing of data collection efforts.

PLANNING AND EVALUATING REHABILITATION SERVICES

Before technologies to eliminate or reduce disabilities and handicaps can be appropriately applied to an individual, that individual must be identified and an assessment made of the nature and extent of the individual's abilities and disabilities. Only then can services be planned, and only in the context of that information can later evaluation of outcome take place. Similarly, only when the service and other technological needs of a population have been assessed can informed planning of resources be accomplished.

The processes in place to do this identifying, planning, and evaluating, as discussed in chapter 3, suffer from various shortcomings. Their substantial, though not complete, reliance on categorical definitions of disabilities has been mentioned above. As the chapters of Part Two will cover, the "need" for *technology is most* often *based on needs* of *disabled persons as perceived by professionals or program administrators instead* of on *a blend* of the *disabled person needs, desires, and capabilities, as identified with the* full *participation of the disabled person or a repre-*

sentative. This situation not only detracts from the process of applying individual technologies but also makes it more difficult to allocate resources at individual, programmatic, and societal levels.

There is great potential for improving this situation through the use of the individualized plans required under programs for education, developmental disability, and vocational rehabilitation. Techniques for creating and carrying out such plans do not, however, appear to be well developed. Nor does adequate effective effort seem to be devoted to making those planning opportunities work.

At the Federal level, OTA finds an apparent lack of attention, and a definite lack of significant funding, given to the use of management information systems based on data from individualized plans. Such information systems could be used to generate data that could be used in planning, evaluating, and modifying programs.