Part One:

Impairments, Disabilities, and Handicaps

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Definitions and Demographic;

I hate definitions.
—Benjamin Disraeli

Round numbers are always false.
—Samuel Johnson

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Definitions and Demographics

INTRODUCTION

Data on impairments, disabilities, and handicaps are not only important as background information but are also critical to the creation and carrying out of policy. There is considerable confusion among analysts, the public, and disability workers concerning a number of definitional and "counting" issues. What is a handicap? A disability? Impairment? How is severity classified? What is the difference between functional and categorical (disease- or condition-specific) classification?

How many people have what types of handicaps or handicapping conditions? Or, how many people have what types of functional limitations? What is the distribution of seventy, whichever approach is taken’? Who is entitled to which programs?

DEFINITIONS

OTA's operational approach to definitional and classification issues starts with the simple idea that society defines, implicitly, a population of "normal" people; that is, people tend to think of the "standard human model" as able-bodied, having what are considered typical functional abilities. Despite the fact that the range of what is considered typical is extremely broad, this concept of normality or typical functional ability still has great power to affect the way people think about other people. In opposition to this concept of able-bodiedness, society defines those individuals who cannot perform one or more of the typical life functions within the accepted range as "disabled" or "handicapped. " The philosophical implications and causes of categorizing people in this way are beyond the boundaries of this study. Still, it is important for policy makers to remember that the type of functional limitations that come to be included in programs for disabled people are based in part on this background concept and are in many cases the result of arbitrary decisions.

For the purposes of this study, an exact definition of a "disability" is less important than the idea that disabilities can be identified and can often be eliminated, ameliorated, or bypassed through technological intervention. For this purpose, a classification scheme based on the idea of functional limitations will usually be more useful to policy formulation than will one based on disease- or condition-specific diagnosis. For example, policies might be more rationally developed and implemented in relation to the need to provide aids for certain types of mobility rather than in relation to the fact that people have cerebral palsy or some other specific condition. And, in fact, the legislation enacted in the last few years seems to recognize this advantage.

OTA finds that the most accurate general term to use in describing a person with some type of functional limitation, given no specific background (contextual) information, is "disabled." A "handicap" has to be specified within its environmental and personal contexts.

Impairment is the basic condition. An impairment is, in the ideal, an identifiable, objectively measurable or diagnosable condition. An impairment is the expression of a physiological, anatomical, or mental loss or "abnormality. " It may or may not be the result of a pathological process. An impairment is the physical or mental, and causal, base of a disability and can be the result of accident, disease, or congenital condition. Impairment implies an "impaired" functional ability of some sort and can be described in terms of cause, severity, population distribution, etc. Impairments can lead directly to disabilities or to a nondisabled state. Loss of an arm through accident is an impairment. If no prosthesis is used or if a prosthesis does not adequately compensate, then the accident victim has a disability, a “dis” (lack of) “ability” to perform certain functions because he or she does not have use of two arms. Disabilities apply to generic or basic human functions: walking, speaking, grasping, hearing, excreting, and so on. It is a much simpler concept and a more objectively measured one than is “handicap. ” The concept of a functional limitation can be placed in clearer perspective when it is divided into the basic or generic function being limited by the disability versus a socially, environmentally, and personally specified limitation, which then becomes a *handicap.*

Aspirations or life goals must be taken into account when defining or identifying a handicap, But the approach to taking these into account must be one based on pragmatism. A person’s life goals and self concept are a legitimate part of the context of a handicap. Society doesn’t tell people that they cannot be computer programmers; the choice of career is for the most part considered a valid personal decision. This view may change when society is asked to pay for the cost of special training, the cost of civil rights or incentives programs to make it easier for a disabled person to be hired, the cost of adapting the computer console, the cost of allowing accessibility to a worksite, and so on. But within a relatively small range, there is little difference in such costs across a large number of career choices. So, if a disabled person *aspires* to an occupation that will present no handicap or a minor one, there may be no problem beyond the ordinary one of preparing for and being hired for that position. If the disabled person *aspires* to one that presents a more severe—or more difficult to reduce, eliminate, or bypass—handicap, that should not be excluded from consideration, because the success of rehabilitation may be increased by personal factors such as being in, or training for, a desired job. The point is that aspirations should not be automatically excluded from the conditions differentiating a disability from a handicap,

Finkelstein gives an example (88):

> A man has had a leg amputated. He therefore is impaired, and since he would have a reduction of his locomotive ability, he is disabled. If, however, he has a satisfactory prosthesis . . . and a car adjusted to hand controls . . . he might well not be restricted in activity and therefore not handicapped.

Technology thus can be used to increase the fit between the individual and his environment. With the use of this formulation of the distinction between “disability” and “handicap,” it becomes necessary to view not only the individual but the context in which he or she operates. A person, therefore, may be handicapped under certain circumstances and at certain times. The disability remains, but the handicapping environment varies. Personal factors, such as poor self concept or a defeatist attitude, may also turn a disability into a handicap.

Although the concept of “typical” abilities can be offensive to disabled and able-bodied people alike, it is an important aspect of the definition process. Without it, such ideas as functional “aspirations” may make identification of the disabled or handicapped population even more difficult. A test of reason must be applied. Playing symphony-quality flute is not a typical level of functioning. People who cannot do so may regard themselves as handicapped, *but that is not likely to be* a matter that society *or its agents consider to be worthy of public intervention.*

DEMOGRAPHICS: THE PROBLEM OF NUMBERS

Another critical issue, closely related to definitions, is that of numbers: the demographics of the numbers and distribution of impaired, disabled, or handicapped people. For example, as described in chapter 11, the allocation of resources is intricately dependent on valid and usable census data of numerous types. These data are also vital for planning and implementing actual projects and programs at all stages of the lifecycle of technology development and use.

There is no dependable count of the *total* number of disabled or handicapped persons. Indeed, such a measure is conceptually ambiguous and methodologically unsound, despite the visibility it may have in public policy considerations. Still, various groups and researchers do spend considerable time in attempting to establish such a count. Estimates range as high as 45 million, including more than 10 million children. Typical lower range estimates are from 15 to 25 million people. Generally, the higher range estimates represent attempts to measure the number of impaired Americans, while the lower ranges represent attempts to count the number with disabilities or handicaps. For example, Butler, et al., report that while approximately 12 percent of all children are affected by some physical or mental impairment, only 3.9 percent have a limitation on daily activities *(26).*

The Butler study also addresses another issue related to “counts. ” Is the number of disabled people increasing or decreasing? Despite advances in technology and the growth of such movements as independent living, it may be that the number is on the rise. As chapter 11 will cover, the percentage of the population that is 65 years and older is rising, and this trend is expected to continue, with resultant increases in impairment and disability. This fact does not have to mean that “handicaps” will increase, but if the current situation with elderly people and the reaction of society to them and their roles and abilities persists, an increase in the number of elderly people might very well mean an increase in the number of handicapped people.

Similarly, there has been a substantial reported increase in the proportion of children with limitations of activity in the past decade. Between 1967 and 1979, the percent of children with some degree of limitation nearly doubled, from 2.1 percent to 3.9 percent. Those seriously limited in function showed a similar increase, from 1.1 percent to 2.1 percent. The reasons for such increases are not clear (and readers should keep in mind the caveats regarding statistics given in this chapter). It is likely that the increased numbers reflect a heightening of public awareness resulting in increased use of services, an increase in the number of children with serious diseases living longer, and artifacts caused by reporting procedures, If the number of children with activity limitations is actually increasing significantly, then the cost of services is also likely to increase *(26).*

Although the overall trend in the numbers of disabled people in the population is difficult to establish, it appears that the numbers are increasing. The challenge, in any event, remains a dual one—to decrease future disabilities while providing the appropriate climate and support for minimizing the effects of existing disabilities (i. e., keeping them from becoming handicaps).

Apart from exhibiting conceptual problems, estimates of the numbers of people with disabilities are plagued by a number of practical deficiencies. Many individuals have more than one disability and thus may be counted more than once. Counts may also be inflated when reported by advocates of people with particular disabilities or impairments—these advocates may select the highest number in a possible range in order to help assure that enough money is allocated to assist all those who *might* need assistance.

Conversely, many people in institutions are sometimes missed in “counts” of disabled people. There are several other reasons why reported counts are sometimes deflated. First, many of the data on disabilities are self-reported. This method has an unknown potential for misrepresentation and bias, but it is generally believed that it leads to underreporting. (In the case of certain impairments and illnesses, such as arthritis and influenza, this method may lead to overreporting,) A related reason is that some people desire to exclude themselves or their children from lists of disabled people to avoid the stigma that is still often attached to being disabled. This may be the primary reason for particular gaps in data pertaining to mental health and to those under 17 years old. Finally, some of the data are collected from places that work with disabled people; *thus,* individuals who are not being worked with or who move are often excluded.

Problems in definition and classification are manifested in attempts to collect demographic *in*formation. Given the range used in defining “impairment, ” “disability,” and “handicap,” it is not surprising that there are many different definitions for words used in describing different *types* of impairments, disabilities, or handicaps. Furthermore, in counting those with a particular disabling condition, it is often difficult to define when the condition is definitely present. For example, epilepsy may cause substantial disability for those affected. Yet it is not always active—epileptics may be cured, or they may be free of seizures owing to treatment. Conversely, the presence of an epilepsy-like seizure does not always indicate the presence of the disease. Different surveyors, however, use different definitions to establish the presence or absence of the disease (81).

Perhaps more important than problems in definition, however, are problems in classification. At their simplest, these problems result from the use of different categories by different authors, so comparability is reduced. Yet the problem is actually more complex, because the types of categories differ widely. The primary difference is whether the disabilities or impairments reported are classified by functional categories or by diagnostic (etiology-specific) categories. Examples of the former include communication and mobility disabilities; examples of the latter include retinitis pigmentosa and spina bifida. Essentially, functional categories provide a context for an impairment by explicitly stating the disability that results. Although functional categories are more descriptive of effects than diagnostic categories, they are equally difficult to standardize.

By focusing on categories of impairments, diagnostic categories often do not provide information on the severity of disabilities. In addition, they obscure the interaction of the environment with the disability and do not distinguish between impairments, disabilities, and handicaps. On the other hand, diagnostic categories do convey some information on whether an impairment is static or progressive and whether it reduces life expectancy—information which is often as critical to policy makers as information on functional ability. Furthermore, these categories are reasonably accurate and have commonly accepted meanings.

It is unlikely that there will be any agreed-upon choice between the two methods of classification. It is important, however, that the type of classification used suits the purpose for which the information was collected.

Surveys of the number of disabled individuals can be deceptive in another way: They often do not distinguish between: 1) mildly disabled individuals, who function at very nearly “typical” levels; and 2) severely disabled or handicapped people, who may be institutionalized, homebound, or critically dependent on a complex of devices and services. Thus, reports that cite very large numbers of disabled people maybe diluting the attention devoted to certain segments of the severely disabled population. Therefore, agencies and organizations that attempt to identify populations needing services should be careful in designing surveys so as to take into account severity and functional status as well as type of disability and handicap.

The preceding problems having been noted, some data on the numbers and impairments of disabled people are presented below. These data are provided primarily as examples to place other problems relating to the development and use of technologies in perspective.

Estimates developed from the 1977 Health Interview Survey provided the following numbers on persons with selected impairments (64): 11,415,000 blind and (at least moderately) visually impaired people; 16,219,000 deaf and hearing-impaired people; 1,995,000 speech-impaired people; 1,532,000 people affected by paralysis; 2,500,000 people with upper extremity impairments (not including paralysis); 7,147,000 people with lower extremity impairments (not including paralysis); and 358,000 people with the absense of major extremities. The total is *41,166,000,* and there are definitely overlaps. Overall, *67* percent of the impairments are found in the categories of blind and visually impaired and deaf and hearing impaired. And, except among those over *65,* there are slightly more impaired males (52 percent) than females (48 percent).

An examination of the working-age population is useful, because an inability to work because of disability results, in our society, in income subsidization or in technological assistance to allow employment. According to the Department of Health and Human Services *(70),* in 1978, of *127.1* million noninstitutionalized working-age Americans, 17 percent, or *21* million, were limited in their ability to work due to a chronic health condition or impairment. While similar proportions of men and women reported some degree of disability, a greater proportion of women were characterized as severely disabled. The prevalence of disability increased with age—adults between the ages of 55 and 64 were 10 times more likely to be severely disabled than adults aged 18 to 34. Severe disability was almost twice as prevalent among the black population as among members of other races. This higher prevalence among the black population is apparent only when all disabilities are considered. If a particular condition is viewed separately, cerebral palsy, for example, the prevalence may be higher among the white population (197). Cerebral palsy also appears to affect people in all economic, social, or geographic categories equally (197), but that is not the situation for *all* disabilities (70). Generally, disabled people are much poorer and less educated than the nondisabled, and this is particularly true in the case of those who are *severely* disabled. As pointed out elsewhere, however, statistics on average earnings and levels of education can be deceptive, based as they often are on people in or known to public and private sector programs. Thus, those people who are less educated and who earn less are those most likely to be counted. This does not mean that there is no problem of low disposable income or of educational level among disabled people; it merely implies that the most successful disabled people may be counted less, with implications not only for resource allocation and statistical bases but also for the development and maintenance of stereotypes and attendant attitudes.