Toward the Necessary Universalizing of a Disability Policy

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WHAT I ARGUE IN THIS ARTICLE IS THAT AN exclusively special needs approach to disability is inevitably a short-run approach. What we need are more universal policies that recognize that the entire population is "at risk" for the concomitants of chronic illness and disability. As the following pages will show, without such a perspective we will further create and perpetuate a segregated, separate but unequal society—a society inappropriate to a larger and older "changing needs" population. It is, however, in the nature of this historical moment that such a change in perspective must take the form of a corrective—a reorientation of the general thinking about disability (Milio 1981).

Two bases for such a reorientation underlie this article. The first is numerical and argues that the problems of disability are not confined to any small fixed number of the population. The second is conceptual and argues that the issues facing someone with a disability are not essentially medical (Hahn 1984, 1985, 1986; Zola 1982). They are not purely the result of some physical or mental impairment but rather of the fit of such impairments with the social, attitudinal, architectural, medical, economic, and political environment.

To establish this perspective, I discuss two features which determine the parameters of current policy: the size and nature of the "problem." I then apply these data as well as existing research to an analysis of existing policies in three essential areas of daily living: housing, transport, and work.

Numbers: How Big a Problem
Is Disability?

Whether the unit of study be a city, a state, or a country, it is generally estimated that one out of eight people has a disability (National Center for Health Statistics 1983; U.S. Office of Technology Assessment 1982). Those numbers themselves (e.g., 36 to 40 million people in the United States) would be of concern; but cast as a ratio, the numbers still convey the notion of a statistical minority. Thus, a major problem is whether or nor such figures are likely to increase (Colvez and Blanchet 1981). Recent declines in various mortality statistics (e.g., the total death rare, infant and maternity mortality, condition-specific death rates), increases in life expectancy at birth, and remaining years of life at various later ages cause many to claim that our nation's health is improving. Time-series studies of chronic illness and disability, however, provide a different and less optimistic picture.

When Wilson and Drury (1984) reviewed the twenty-year trends (1960 to 1981) in fifteen broad categories of chronic illness in the United States, they found that the prevalence of seven conditions had more than doubled; two had increased their prevalence from 50 to 99 percent; five had increased by up to 50 percent; and only one condition had become less prevalent. The so-called "graying" of the population did not explain this phenomenon, since a similar pattern was observed for persons aged 45 to 64. For this latter group—the core of the working population—their chronic conditions translated into activity limitation, with a more than doubling (from 4.4 to 10.8 percent) of the number of males who claimed that they were unable to work because of some illness or disability.

Looking at two subsets—the young and the old—is particularly instructive. While the absolute number of children (under 17) is not expected to increase, the proportion of those with a disability will. The United States National Health Interview Survey (Newacheck, Budetti, and Halfon 1986) indicates that the prevalence of activity-limiting chronic conditions among children doubled between 1960 and 1981 from 1.8 to 3.8 percent, with the greatest increase in the last decade. While much of this may be due to the survival of lower-weight new-borns with various impairments, the major increase may well be due to shifting perceptions on the part of parents, educators, and physicians. Health care professionals often refer to this as "the new morbidity,"

a trend away from the concern of pediatric practice with traditional medical illness toward greater interest in more psychosocial issues, such as behavioral adjustments and learning difficulties (Haggerty, Roghmann, and Pless 1975). Although some have argued that this new concern results in part from the increased supply of pediatricians needing new territories in which to practice, it has been reinforced by the growing attention of other health professionals, educators, and the general public to learning and other educational difficulties. Renewed worldwide efforts at mainstreaming children with disabilities has sharpened this focus. In fact, while United States census data from 1970 to 1980 show little change in the number of children residing in institutions for physical disabilities, there were reductions in the numbers of children residing in institutions for mental disabilities. Hence, it appears that the recent increase in prevalence of learning disabilities among noninstitutionalized children may be explained by increased detection efforts and heightened awareness of educational problems, as well as by efforts to deinstitutionalize and provide mainstream education to children with mental retardation (Newacheck, Budetti, and Halfon 1986). It is also clear that changing educational concerns are making learning disabilities (e.g., dyslexia) the fastest growing disability on college campuses (Faigel 1985). What new learning disabilities will be discovered when computer literacy becomes a sine qua non for success in contemporary society is anybody's guess.

In absolute numbers, the older population is growing in number throughout the world. All census data affirm that the fastest growing segment of the United States population is made up of those over the age of 65. In 1880 their number was less than 2 million (3 percent) of the total population, but by 1980 it was over 25 million (11.3 percent). By the year 2030 an estimated one in four or five citizens (20 to 25 percent) is likely to be over the age of 65 (Gilford 1988). Put another way, throughout most of history only one in ten people lived past the age of 65; now nearly 80 percent do. This traditional use of age 65 as a benchmark, however, is deceptive, for the most phenomenal growth will be in the even older age groups, those over age 85. This group, while constituting 1 percent of the total population in 1980, is projected at 3 percent in 2030 and over 5 percent in 2050. At that time they could constitute nearly one-quarter of all elderly people (Gilford 1988). The service implications are worth noting. For, while 3 to 5 percent of those aged 65 to 74 require assistance in basic activities of daily living, over

one-third do so by age 85 (Feinstein, Gornick, and Greenberg 1984; National Center for Health Statistics 1983).

Nature: Is Disability the Same as It Always Was?

For years infant mortality has steadily decreased, in large part because of improvements in standards of living and prenatal care. Recently, these improvements have been supplemented by advances in the specialization of neonatology. Though the numbers are as yet small, it is clear that there are increasing numbers of low-birth-weight and other infants surviving into childhood and beyond with manifest chronic impairments. With advances in medical therapeutics, many children who would have died from diseases ranging from leukemia to spina bifida to cystic fibrosis are now surviving into adulthood or longer. Diagnostic advances, as well as some life-extending technologies, allow many young people to survive with so-called "terminal" illnesses.

There is a similar trend evident in the young adult group. While trauma still continues to be a major cause of mortality in this group, there is a major turnaround in the survival rates of people with spinal cord injuries. As recently as the 1950s, death was likely in the very early stages or soon after because of respiratory and other complications. Thus, in World War I only 400 men with wounds that paralyzed them from the waist down survived at all, and 90 percent of them died before they reached home. In World War II, 2,000 paraplegics lived and 1,700—over 85 percent of them—were still alive in the late 1960s (President's Committee on Employment of the Handicapped 1967). Each decade since has seen a rapid decline in the death rate and thus an increase in long-term survival—first of those with paraplegia, then with quadriplegia, and now, in the 1980s, those with head injuries.

At the moment, the situation with the older population may seem less predictable. At the very least, we can speculate that an aging population will be even more "at risk" for what were once thought "natural" occurrences (e.g., decrease in mobility, visual acuity, or hearing) and for other musculoskeletal, cardiovascular, and cerebrovascular changes whose implications are only beginning to be appreciated. On the other hand, with the advent of other therapeutic and preventive advances, some predict an extension of fitness at middle age. According to Fries (1980) and others,

however, this will not eliminate disease and disability but rather be a "compression of morbidity" toward the end of the life span. This would argue for a possible decrease in the length of time that the older population will have one or more disabling conditions. Conversely, Kramer (1980) and Grundy (1984) feel this flies in the face of the ongoing and strong general correlations between growing older and chronic disease and disability as well as a general societal tendency to invest resources and technology in keeping such people alive (Blanpain 1985; Callahan 1987). Gruenberg (1977) more cynically refers to this phenomenon as "the failure of success."

Still another unappreciated aspect of most chronic conditions is that although permanent, they are not necessarily static. While we do, of course, recognize at least in terminology that some diseases are "progressive," we are less inclined to see that there is no one-time, overall adaptation/adjustment to the condition. Even for a recognized progressive or episodic disorder, such as multiple sclerosis, attention only recently has been given to the continuing nature of adaptations (Brooks and Matson 1987). The same is also true for those with end-stage renal disease (Gerhardt and Brieskorn-Zinke 1986). With the survival into adulthood of people with diseases that once were fatal come new changes and complications. Problems of circulation and vision for people with diabetes, for example, may be due to the disease itself, the aging process, or even the original life-sustaining treatment (Turk and Speers 1983). Ivan Illich (1976), in particular, has drawn public attention to the iatrogenic costs of many medical interventions—costs that may show up only after many years, as one ages, or all too frequently in subsequent generations. A form of vaginal cancer in children of mothers who took the drug DES to prevent miscarriage is perhaps the best known recent instance (Apfel and Fisher 1984).

Perhaps the most telling example of a new manifestation of an old disease is the current concern over the so-called post-polio syndrome (Laurie and Raymond 1984). To most of the public, to clinicians, and certainly to its bearers, polio has been considered a stable chronic illness. Following its acute onset and a period of rehabilitation, most people had reached a plateau and expected to stay there. For the majority, this may still be true, but for at least one-quarter of them, it is not. Large numbers of people are experiencing new problems some 20 to 40 years after the original onset. The most common are fatigue, weakness in muscles previously affected and unaffected, muscle and joint pain, breathing

difficulties, and intolerance to cold. Whether these new problems are the mere concomitant of aging, the reemergence of a still lingering virus, a long-term effect of the early damage or even of the early rehabilitation programs, or something else, is still at issue (Halstead and Wiechers 1985). Whatever the etiology of this phenomenon, there will likely be many more new manifestations of old diseases and disabilities as people survive decades beyond the acute onset of their original diseases or disabilities (Funne, Gingher, and Olsen 1989; Sato 1989). Thus, the dichotomy between those people with a "progressive" condition versus those with a "static" one may well be, generally speaking, less distinct than once thought and indeed be more of a continuum.

   Still another source of change is the fit between any impairment and the larger social environment. Simply put, some physical differences become important only in certain social situations (reading and writing difficulties where literacy or speed in literacy is deemed "essential" to success or mobility impairments in a sports-oriented society) or at certain times of life (sexual and reproductive issues are less important for the very young and the very old, and some for only one gender). The life-cycle theorists are quite aware of this and postulate different issues one must contend with and the resulting disablements if one does not. Yet, many of these theories and the resulting social policies are locked into a grid where the "final" stage of life begins around age 65. This might have been at least logical when the general life span was much shorter; then, each stage took about ten years (i.e., the seven stages of "man," covering three score years plus ten). But what does it imply when the "last" stage is "occupied" primarily by women (Doress and Siegal 1987) and continues far beyond a decade, with some (Gilford 1988) estimating it could reach forty years or more? Surely neither society in general nor the individuals involved will tolerate one stage of life that covers nearly one-half of the life span. Later life is clearly an uncharted map that will inevitably bring new challenges requiring different capacities and evaluations (Katz et al. 1983) but also involving new diseases, problems, and disabilities.

   The previous pages provide the data base for what is to follow. To this I will add a synthesis of existing research as I analyze the policy options in regard to three areas of daily living essential to people with disabilities and which cut across all ages, genders, and socio-economic status. They are housing, transport, and work.

Housing and the "Built Environment": How
Can Society Guarantee People the Largest
Options in Their Living Arrangements,
Both Now and in the Future?

When speaking about the housing needs of people with disabilities, it
is well to remember the cautions of Lifchez and Winslow (1979)—that
we are talking about more than the needs for access in and out of where a
person lives. A term with certain currency today is reference to the "built
environment," defined broadly to include both all the established ways
we design our inner dwellings (the heights, widths, and depths of our
doorways, sinks, tables, and closets) as well as the byways to and from
the rest of a person's external world (Phillips 1983). Where once housing
for older people and those with disabilities referred exclusively to some
sort of long-term care institution or functionally segregated area (e.g.,
retirement communities, villages for certain "diseases" and disabilites),
today it does not.

   A recent study in Houston, Texas—one of the most detailed done
on the housing needs of low-income people who are elderly and have
disabilities (Gilderbloom, Rosentraub, and Bullard 1987)—found that
one out of every ten Houston residents requires special architectural
modifications in their homes. One-third of the older residents and over
one-half of the people with disabilities require grab bars and at least 20
percent need ramps. This need for ramps and railings doubles as people
move from the group aged 60 to 65 to that aged 75 and older, where
one of three need ramps and one-half need railings. For those with a
"severe" as opposed to "moderate" disability, two-fifths need ramps and
one-third need railings. Given the numbers, it is not surprising to find
that 25 percent of those who are over the age of 65 and have disabilities
would like to move from their current home in the next year.

   What is optimistic, however, is how largely correctable such problems
are, and for small costs. If accessibility is incorporated into the design
prior to construction, the costs of accessible units are only slightly more
than conventional ones (Dunn 1985a, 1985b). According to the Batelle
Memorial Institute (1977), the cost of a barrier-free design can range from
.25 to 4.2 percent of the fixed costs, depending upon the type of units
to be made accessible and whether it is new construction or renovation.
The average cost of making 10 percent of newly constructed units of an

apartment dwelling accessible is less than 1 percent of construction costs. Estimates made by the Society of Landscape Architects indicate that the exterior environment which interfaces with housing—such as steps, handrails, parking, and site lighting—can be made accessible along with the interiors of buildings for slightly more than 1 percent of construction costs when incorporated in the initial plans (Robinette 1978).

By the time of this article's writing, inflation may have raised these estimates. They will also vary, depending on expanded and developing standards of accessibility and how much any specific adaptation will "necessarily" lead to other changes (e.g., increase in apartment size). Thus, a recent *New York Times* article (Richman 1988) claims that compliance with Local Law 58, "a law that requires nearly every new or substantially renovated apartment to be designed for the disabled," would add "5 to 8% to costs." On the other hand, as such design installation and equipment features become more commonplace, the actual cost (because of government and insurance company support as well as business interest) is likely to go down and the value of the property to increase (the latter is not idle speculation, as I discovered when filling out my United States tax forms, to account for a newly constructed outside ramp and a wheelchair-accessible bathroom!).

Even with a retrofit situation, the options are more viable than ordinarily realized. Peter A. Dunn (1987) evaluated Project Open House, a program which adapts homes of a wide spectrum of people with disabilities in the New York City area. In this group of clientele the physical access in and out of the homes, and aids relating to toileting, bathing, and grooming (all usually in bathrooms), were the two most important housing adpatations. The latter had a most direct effect on one of the most "troublesome" aspects of the care of both older people and people with disabilities—their independence in matters of personal hygiene. The former adaptation had a direct effect on people's spending more time in community activities and an indirect and complex effect (i.e., in that *other* factors were also important) on their employment. Striking also was the effect on household members, reducing many physical, emotional, and energy strains on them. In general, the older the individuals, the more important such adaptations were, because these people were more likely to be relying on other older people's assistance (e.g., spouses and aging parents).

For the vast majority of people with disabilities, these adaptations improved their feelings of safety and security and helped ensure their

continued residence in familiar surroundings among friends, family, and community. An important caveat, however, in line with the previous point about the changing nature of disability, was that within a couple of years, some 40 percent of the clients' needs had changed. It is not clear how much of this was due to new needs created by new possibilities or new needs created by changing health conditions. On the other hand, all of these adaptations were achieved at an average sum of $1,507, an amount which in several cases was equivalent to a year's cost for ambulance service and stretcher bearers for those in inaccessible housing who required frequent medical attention.

Ratzka (1984) has extended the implications of such work in terms of much more costly "adaptations" like the installation of elevators. In Sweden he finds such renovations are 40 percent less costly than the institutional care they replace and estimates that as much as 40 percent of the moves of people with disabilities into nursing homes could have been avoided by housing modifications. Ratzka also examines the issue of long-term costs. In the 1930s, fifty years before his report, there was apparently a debate on whether to include elevators in the housing project area in which he concentrated his analysis. If included, the resulting increase in break-even rents would have been 3 percent. A comparison of these additional costs with the costs of *not* making housing accessible showed that *each year* Swedish society is losing over SEK 160 million (approximately 40 million U.S. dollars), for a total of some SEK 5,800 millions (approximately 1,450 million U.S. dollars) "wasted" by the 1980s. All in all, it cost thousands of times more than what the original investment might have been. Deborah Chollet (Dunn 1987) estimates that renovated housing in the United States yields benefits in terms of reduced support services, amounting to thirteen to twenty-two times the levels of cost, and Beatrice Lewis (1985) documented similar benefits vis-à-vis children.

The current nature of our built environment may even have a direct etiological effect upon the "production" of disability. Accidents are generally regarded as one of the most preventable causes of disability. While public attention is often focused on traffic accidents, except for the teenager and young adult group, the home is the major location. This increases directly with age. In both Sweden (Ratzka 1984) and the United States (National Safety Council 1980), persons of the age of 65 or older account for more than 75 percent of deaths due to falls, even though they compose less than 15 percent of the population. The

population over the age of 65 has more accidents in the home *than in all other places combined* (Collins 1985). The vast majority of these were falls on staircases and slips on wet surfaces such as in bathrooms (Collins 1985). Any public policy which would upgrade the safety standards of all entrance and toilet facilities (e.g., the requirement of nonslip surfaces and grab bars as standard equipment near toilets and in baths and showers) in all public accommodations (especially hotels) and encourage such adaptations in the private sphere (as with tax breaks given to those who insulate their houses during the "energy crisis") could lead to dramatic increases in the prevention and postponement of certain disabilities.

A physical environment more flexible in orientation (i.e., not designed exclusively for able-bodied users) and more flexible in design (e.g., more adjustable in height and placement and reflective also of a range of cognitive and sensory needs) requires as much a change in perception as in architecture. If society perceives that the needs and abilities of people are constantly changing, it might alter its attitudes toward the built environment from one of "permanence" and "maintenance" to one of "flexibility" and "adaptation." This is, in fact, what happened at Het Dorp in the Netherlands (Zola 1982), where such an expectation was part of the design for "this village" of people with varying and changing abilities. Thus, the village had a general crew of workers whose major task was to be available "to adapt" the built environment (in and out) to the changing needs of the residents.

Transportation: What Are the Problems of Getting from Here to There?

Speed, endurance, and access have generally been the stimuli for the creation of transportation modes and systems. Thus, when either time, physical strength, or location (e.g., the destination is across an ocean or to a plateau of an unclimbable mountain) has been a problem, individuals have then sought some mode of travel other than walking.

Within this framework, a wheelchair is just another way of moving from one location to another. The degree to which it has been designed for self-propulsion rather than for someone else to push it has always reflected more society's view of the individual's "condition" (Biklen and Bailey 1981; *Disability Rag* 1984) than of the person's own physical ability. Current vocabulary reflects society's ambivalence as such users are often

referred to as "confined to" or "wheelchair-bound" (Zola 1989). The view of a wheelchair as just another way of getting around is more than political rhetoric and has appeared in a novel by one of America's most popular authors, Elmore Leonard (1983). *La Brava* contains a recurring character in a wheelchair. Only in mid-novel does the reader learn that this use is not due to any "medical condition" but because the character thinks it's a "nifty" way to travel. A similar change in the public perception would have great implications.

Large segments of the population currently avoid wheelchair use, even temporarily, because of its perceived stigma (*Disability Rag* 1984). Thus, many older people reject it because it defines them as "frail" and "invalid," as do many others with mobility "problems" (Zola 1982) who could benefit from it situationally (e.g., in airports or any place where distances or standing for long periods is involved). There is no design reason that wheelchairs need be so "medicalized" in appearance (the classic heavy metal look). Here, the popularity and visibility of the wheelchair marathoner is having a major impact. Their need for slender, lighter vehicles has led to the exportation of these features into the more general marketplace, where they have led not only to sleeker and lighter models but also to different colors and fabrics and to the add-on features and "creature comforts" usually thought more relevant to cars. This, in turn, will reduce the stigma and make wheelchairs more appealing to the general public.

A more mainstream sports influence is evident in the use of golf carts, introduced to ease the strain of walking and to spare energy between holes. Though their use has recently become controversial in tournament sports, their general acceptance has influenced the use and design of other kinds of motorized carts and scooters (e.g., the Amigo in all its variations) as well as new adaptations of an even older recreational vehicle, the bicycle. Devices and changing seat design allow for pedaling by hand and in more reclining positions. It does not take much imagination to realize that further adaptations of the "motorized bike" are bound to follow. All these models of transportation are already popular as general (as opposed to recreational) travel outside the United States and thus require no new or special technical or societal reorientation (e.g., bike paths already exist parallel to many roads).

While there is, of course, some need for high-technology investment in rough terrain and even stair-climbing vehicles, the more universal need is for a more generally accessible environment and for less expensive,

flexible, and more easily maintained and self-serviced wheelchairs. Working with cultures as disparate as Nicaragua, Peru, the Philippines, and India, Ralf Hotchkiss (personal communication 1987) has designed a wheelchair which can be made "anywhere there is the technology to fix a broken fender" and at a cost of between $100 and $250 (Hotchkiss 1984, 1985, 1986).

The privately operated automobile is, however, the preferred mode of transportation in the United States and in certain parts of the industrialized world. It is clear that the technology exists to adapt almost any motor vehicle to the transport of people with disabilities (e.g., the transfer of persons from wheelchair to a regular seat or, with the growing popularity of vans, the "wholesale" transfer of one or more individuals in wheelchairs). For people with paraplegia and other spinal cord and mobility involvements, some form of lever device has usually been sufficient to allow them to drive their own vehicles. (Franklin Delano Roosevelt, perhaps the most famous wheelchair user, drove with such a device over 50 years ago.) The devices currently used in battery-driven wheelchairs (e.g., joysticks) are increasingly being adapted for people with a very wide range of disabilities. With the perfection of breath-controlled wheelchairs, the introduction of such devices in other vehicles may just be a matter of time. Most important, much of what will assure the continued accessibility of cars, vans, and trucks to people with physical disabilities will not involve special design. Universal features or regular add-ons—such as automatic shifts, cruise control, power steering and brakes, electronically operated windows and seats, glare control (i.e., an aid to low or night vision problems), flashing and voice signals—as well as any other device which may be "push-button," "finger-tip," or voice activated, as well as many improved features (Committee for the Study on Improving Mobility and Safety for Older Persons 1988), enormously ease the task of driving for *all* of us, but especially people with varying disabilities.

As we move into areas of mass transportation, however, the solutions and the costs become more problematic. Of all the areas of life where integration and accessibility are called for, mass transportation is arguably the most costly, in economic and psychological terms, for the society. Taking minimal estimates of cost, the creation of new accessible transport (be it cars, buses, trains, or planes), the retrofit of existing models, or the provision of alternative ones (e.g., purchase of private "modified" cars and vans, contracts with private purveyors such as taxis or special services, including paratransit) involves considerable expenditure in the

initial creation, purchase, modification, and maintenance. Whether this makes it "prohibitive" clearly depends on whose data and assumptions one relies (Bowe 1983; Katzmann 1986; Petty 1987) and what priorities a society chooses to set.

The documentation of the present inaccessibility of the mass transportation system, be it local (Gilderbloom, Rosentraub, and Bullard 1987), state (Governor's Commission on Accessible Transportation 1987a and 1987b), or national (DeJong and Lifchez 1983), is clear. While "accessible" housing provides the baseline for an independent and heterogeneous population, the ability to reach the rest of one's environment and facilities (from places of training, work, and play to the necessary support and medical services) is impossible for much of the citizenry (particularly the poorer, the older, and many of those with disabilities) without accessible mass transportation.

In regard to airline, boat, and train travel, the modifications to existing systems or to new ones are relatively modest in cost and technology. Wider aisles, seats, and toilets, removable arms for easier transfer and leg room, inflight transfer chairs, more grab bars, visual and auditory aids, the return of "family fares" (i.e., reduced costs for additional passengers such as personal attendants) are just a few examples. An instance of a more universal change is in the general improvement of air circulatory systems and the increasing regulation of smoking—features that affect the current health of anyone with a respiratory or sinus or allergic difficulty and the future health of the rest of us.

The more troublesome aspects of mass transportation exist in the "local" manifestations of these modes: the frequently stopping trolleys, buses, and trains. While several commentators have referred to these as the acceleration and deceleration features (Bowe 1983; Kinley 1987), such a technical designation may inadvertently mask deeper societal value issues. As stated at the beginning of this section, in most parts of the world this transportation is used to get somewhere quicker. Though a value on time and speed does vary cross-culturally (Kluckhohn and Strodtbeck 1961), it seems part and parcel of contemporary views of industrialization and, thus, the "modernization" of many parts of the world. Such cultural clichés as "time is money" and "the quicker the better" play themselves out not only in building faster vehicles and quicker accelerations, but are also germane to other areas of mass transportation such as the speed of train and public elevator closing doors, traffic lights, and pedestrian signals.

It is not accidental that in writing about transportation I have not fo-
cused on the renovation of existing facilities, something which is given
considerable attention in regard to the built environment (i.e., housing).
The latter may literally last "forever" and certainly during any given in-
dividual's lifetime. Many may even wish to live and die in the same place
that they were born, raised children, etc. In other words, because such
stock is not easily replaceable, despite its solidity, it must necessarily be
"rebuilt." On the other hand, the "life" of many machines, particularly
vehicles, has a more finite existence; some even claim planned obsoles-
cence, and it is harder to adapt most vehicles *after* the initial ordering
(i.e., it is more difficult to add air conditioning to a car than to a house,
to widen a house vs. a car door, or even to add more automatic features
such as cruise control and most of those mentioned previously).

The nature of mass transport demands a public policy commitment
since it involves such matters as the creation and maintenance of byways
and highways, the standardization and regulation of features to assure
safety, the increasing recognition of its ecological implications (e.g.,
various pollutants), and its truly "mass" aspects, not only in terms of
numbers of users but in the fact that transport involves the crossing of
local, state, and national borders. The specifics of this implementation,
however, may be less clear cut than in other areas. Experience in the
United States, however, has shown that its solution (at least on the
mass level) cannot be left solely in the hands of private enterprise and
initiative (e.g., the argument that it costs too much to develop, produce,
and maintain certain services), nor its implementation to "local" control,
design, or option.

Mass transportation by definition is a "fixed route" phenomenon. As
such, there is always the issue of getting from one's "home" to "the
mass" aspect of the system. It is here that privatized solutions (though
not necessarily without governmental or public policy input), such as
para-transit van systems or subsidized taxis, have traditionally filled the
gap. To date, such private modes have had great constraints on their
availability: they cover very limited geographic areas, have very limited
time usage (often closing down at 6 p.m.), set priorities on the nature
of usage (medical vs. recreational), restrict their frequency (number of
times per day or week), and require considerable preplanning (in some, a
week's advance notice). In no instance of which I am aware do they have
the almost universal availability and immediacy of a taxi, nor are they
cost-efficient per usage. On a social level, systems like this, no matter

even if operated more efficiently on all these dimensions, will always have a negative consequence; for, by their very nature, they promote and sustain segregation, not integration.

Mass transit may also involve deeper and less "admissible" psychological issues. In the short run, involving as it does great physical proximity, mass transport may evoke the deeply held fears of many in the general population about contact with and contagion from people with disabilities (Livneh 1982). In the long run such forced proximity may in itself deflate some of these same myths, particularly when the myths are based more on lack of knowledge and contact. A few years ago, as part of a protest against the inaccessibility of a local train station, I and many others rode the rails and handed out leaflets. To a child's question of what such people as we in wheelchairs were doing on the train, the mother patiently explained, "They need to get to work and go shopping, just like we do."

Work: A Question of the Who, the What, and the Where

While some futurists argue that paid work will remain a major source of sustenance, personal or economic, for generations yet to come, few will deny the shrinking of the work day and work week. There may also be a general shrinking of one's paid work life. Thus, in the United States the median age of retirement among private-sector workers is now 62, and projections indicate that the age level is going down (U.S. General Accounting Office 1985). It does not seem unreasonable to think of this as one indication that this population ranks work as a less important priority in their lives and is increasingly able to act upon this judgment. Add to this the fact that with the perceived need for universal education and training, people are entering the paid work force at later ages. Thus, together with leaving work earlier and living longer, people, in general, will spend more time outside the work force than in it. Moreover, all the productive unpaid roles in the home, the family, and in voluntary associations are likely to assume even more importance.

In heralding the importance of "unpaid work," the women's movement is now joined by the "Independent Living Movement." The latter, while not necessarily eschewing the importance of work, does, however, decry the traditional emphasis on measuring rehabilitation potential almost

exclusively in work terms (Stubbins 1982, 1987; Cornes 1984). For the Independent Living Movement, success and independence are measured in terms of an individual's control of his/her own life and the ability to make decisions (Crewe, Zola, and Associates 1983; DeJong 1983; Scotch 1984). This may well have the effect of bringing about a reexamination of habilitation and rehabilitation being so closely linked to a work outcome and benefits tied to work-based status.

Some claim that with the end of the baby-boom era, there will be a shrinking population available for work and thus a greater premium on all those previously excluded or underemployed (e.g., minorities, women, people with disabilities). Yet, studies show that these groups, even though they may be professionals (Lorber 1984), enter at the lowest rung of their occupations (Cornes 1984). Moreover, while people with disabilities may be less disadvantaged in the abstract (i.e., computer literacy and usage are relatively "friendly" to this population), it will require a massive change in attitudes of society as well as their agents—in this case, vocational rehabilitation counselors (Stubbins 1982, 1987)—to support the increased expenditure and education which are necessary for these new jobs.

On the other hand, any structural change or policy initiatives which make work hours more flexible, increase part-time employment with no concomitant loss of benefits or pay scale, and decentralize tasks will also enhance the employability of people with disabilities. As automation and new technologies take over the production of goods, both in the factory and the office, future jobs will depend less on labor-intensive, people-to-nature, and machine interactions. In the "postindustrial" society, greater premium will be placed on knowledge than on physical strength or craft skills. Human capital will form the core of the new service economy (information technology, communications, health, education, social service, and leisure activities). While the "capacities" necessary for such work bodes well for people with disabilities, the general shrinking of the labor market, both in absolute numbers and length of full-time employment, may prove a mixed benefit (e.g., unions and other employee groups may resist their incursion into the work force, as might employers because of insurance costs).

Flexibility in work time and a decrease in work hours will make it easier for anyone with limited energy, or anyone who requires long preparation to get ready for and travel to work, or anyone whose condition requires many breaks or "time-outs" in a schedule. Still another change

(really a return to a previous era), the opportunity to do work at home, will have major implications. By 1980 it was estimated that 12 percent of all British companies employ staff who work at home, using terminals linked to central computers (Cornes 1984). While this, too, may make it still easier for people with limits in energy level to set appropriate work schedules, it will also open up varying work settings which, because of distance or architecture, were previously inaccessible. Thus, as work in general becomes even more computerized and decentralized, it can only enhance the work potential of anyone with a disability.

Another perspective on the relation of public policy to work emerges with a demographic focus on "the work disabled." As Vachon (1987) notes, of persons with a disability *not* in the labor force, only 7 percent have never been employed. On the contrary, 93 percent report some previous employment. One conclusion from this is obvious: A key element in any policy would be to *prevent* persons with disabilities from leaving the work force and sustain their participation as long as possible. Though the data are scanty, what exists is provocative.

Certainly a major factor affecting the continuance of employees is current health cost, coverage, and financing—considerations quite amenable to public policy. Data on health care costs to industry are indeed "explosive" (Nash 1987, 12). Unfunded liabilities for employee health care have been estimated to range from $98 billion to $3 trillion— a "corporate time bomb" because the liability for some companies exceeds their current net worth. Thus, many corporations and other organizations, fearing the implications of an aging work force (Paul 1984), are reviewing their benefit packages and rewriting them to pass on more of the cost to the individual employee. On the other hand, it may well be possible to "spread the risk" by increasing the pool of coverage on national or international levels.

An example of this pooling had an interesting and short-lived history in the United States. Until 1984 United States law included an incentive to hire workers aged 65 and over by making Medicare accessible as their primary health insurer (Nash 1987). This saved the employer not only the direct cost of that insurance policy, but, given the higher usage of medical services—including aids and other forms of reimbursable assistance to this group—it forestalled other increases in employer costs, as rising expenditures are usually pushed back eventually to the consumer. (It is worth noting that increases in health costs do not necessarily parallel

any decrease in productivity [Louis Harris and Associates 1987; Rhodes 1983].) But in 1984, under a new administration, the Congress reversed itself, and current law requires the employer of older workers to be the primary insurer of health costs. In such a manner was an incentive to the retention, if not hiring, of older workers with a disability turned into a disincentive.

   In terms of economic costs from early retirement or the loss of skilled employees or lost productivity because of unattended and unaccommodated disability, it is in the interests of employers to retain such people (Mitchell 1987; Perlman and Austin 1987). A general review of workers who withdraw from the work force prior to retirement indicates that health problems are the major reasons for their cessation (Kingston 1982). What is even more informative is the nature of such health conditions. Arthritis has replaced heart disease as the major adult disabling condition, and together with its most common functional counterpart, backache, these are identified (Yelin, Nevitt, and Epstein 1980; Kramer, Yelin, and Epstein 1983) as the major problems of the working-age population. Thus, over their lifetime 52 percent of the work force being treated for arthritis will report significant work disruptions, and 80 percent of the working population will have their ability to work disrupted by backache at some point. Yet, the mere presence of such functional incapacity or the medical condition per se were insufficient factors for withdrawal from the workforce. As Liang et al. (1984) and Yelin, Nevitt, and Epstein (1980) report, among individuals with rheumatoid arthritis, job flexibility and work satisfaction (and Kingston 1982 would add "self assessment of the capacity to work") were found to be very influential in predicting successful continuation of work among older workers. Thus, with such wide prevalence of just this physical condition, arthritis and its concomitant, it seems that work-place accommodations—including greater accessibility, health promotion, and exercise programs, greater attention to seating, and other design factors—might permit the continuance of many workers who would otherwise feel it "necessary" to leave.

   A Louis Harris and Associates (1986) poll reports that the vast majority of those employees with a disability did not acknowledge this fact at work. Whether it be fear of discrimination or stigma, they simply did not self-disclose. At the very best, this must mean that if they undertook *any* work modifications, they were minimally visible, as were any attentions their conditions might have warranted while at work (from special diets,

medications, different pacing, or rest). From past data on "mainstream adapters" who felt the necessity to in some way hide their disability, we may speculate that many of these workers felt the need to overcompensate or "pass" and thus may inadvertently have negatively affected their own conditions.

Attention to such workers and their disabilities could have "a trickle-down effect." Anything that enhances these employees' ability to "come out" at work will likely make easier the integration of "the never-employed" person who has not necessarily a "more medically serious" disability but, generally speaking, a more visible one. Any general implementation of design modification of access and task will similarly open up the work place, eliminating some obstacles (e.g., entry) to participation and making other adaptations seem less "special." Modifications may even have positive effects on the work of other workers. Akabas (1984) cites a November 1983 "Labor Letter" column in the *Wall Street Journal*, which reported that when Tektronix altered an assembly line supervisor's task to aid a man with mental retardation, all 12 workers' output rose and errors fell!

Public policy in the arena of work seems to have focused more around single efforts for single individuals in single work places, adapting the work place to the specific and often unique needs of that individual. Thus, where work is concerned, policies need to shift from exclusive emphasis on employability to a broader concern with existing disincentives facing both the potential employer and employee (Berkowitz 1980; Griss 1985). Placing disability in a wider context of the entire work force creates the possibility of wider interventions of public policy, with emphasis also shifting from the worker to the work place and the general nature of work.

In Conclusion

What I have tried to do in this article is demystify "the specialness" of disability. By seeing people with a disability as "different," with "special" needs, wants, and rights in this currently perceived world of finite resources, they are pitted against the needs, wants, and rights of the rest of the population (Stone 1984). It is clear that much has been achieved by recognizing that people with a disability have long been treated as an oppressed minority (Hahn 1984, 1985, 1986) and that much can be

gained by using a civil rights strategy to enhance and clarify the rights of people with disabilities (Scotch 1984, 1989). On the other hand, as Barnartt and Seelman (1988) have pointed out, such an approach does have its limitations. I have argued in this article for an additional, complementary strategy. Only when we acknowledge the near universality of disability and that all its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated will it be possible fully to appreciate how general public policy can affect this issue. Such a turnaround is easier said than done (Milio 1981).

Thus, as Borgatta and Montgomery (1987) point out, to reexamine policy means to reexamine our basic values. There is a growing recognition from providers of service themselves (Katz 1984; Osberg et al. 1983) and designers of the environment (Lifchez and Winslow 1979; Lifchez 1987) of their role in the creation of past problems and their necessary role in future solutions. But it is more difficult to think of the problems of health, disease, and disability on a basic social-political-economic level. While it has long been recognized that access to certain health resources will be affected by social, political, and economic factors, it is less accepted that the very health problems themselves may be created (Navarro 1976; Waitzkin 1983) and even perpetuated (Illich 1976; Illich et al. 1977) by those same forces. It is thus no accident that medicine as an institution (Starr 1982) and medicalization as process (Conrad and Schneider 1980; Zola 1983) hold such sway in the 20th century. For the focus on the individual disease, the individual patient, the individual treatment becomes at the same time a powerful depoliticizer of all the other external forces (Crawford 1977; Zola 1972).

The power of an institution is often reflected not in the possession of formal power but in the influence it holds in the minds of the population (Zola 1983). Thus, after contact with medical institutions, people, both in and out of hospitals, tend to think of themselves and be thought of by others in terms of their diseases and disabilities (Gartner and Joe 1987; Kadushin 1969; Zola 1986). The first step to changing this situation is when the people themselves begin to question such images and such institutions (Boston Women's Health Book Collective 1984). The Independent Living Movement (DeJong 1983; Scotch 1984) has been in place for over a decade, but the first evidence for a changing consciousness on the part of a larger population is only now at hand. The Louis Harris and Associates (1986) poll of a national sample of people with disabilities indicated for the first time the beginning of a kinship across

disabilities, the identification with the minority status of blacks and Hispanics, and a recognition of the long-term denial of their civil rights. I have no idea how widespread such a feeling is, but the movement is now cross-cultural with the formation of Disabled People's International in the early 1980s.

And so I return to where I began—with the notion that a universal policy toward disability is not only a concern but in the interests of an entire society. What such a society might look like was examined by the Swedish Secretariat for Future Studies (1982) in a document aptly called *A Caring Society*. This report, while recognizing each person's uniqueness, also acknowledges their interdependence and promulgates a concept of special needs which is not based on breaking the rules of order for the few but on designing a flexible world for the many (Lifchez 1987; Orleans and Orleans 1985). In short, what is done in the name of disability today will have meaning for all of society's tomorrows.

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