RTC/IL MONOGRAPHS IN INDEPENDENT LIVING

Economics and Independent Living

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Abstract: Drawing upon his extensive background in the independent living movement and the writings of social historian Alvin Toffler, Gerben DeJong argues that economic independence, when broadly defined, is as important, and in some circumstances more important, than more traditional health outcomes such as performance of basic daily living activities. DeJong asserts that true economic independence, which he defines as the ability to be self-directing in one's work, can be sought and achieved through two types of work: paid work done by people for sale or swap and unpaid work done by people for themselves, their families, or community. In this broader sense, DeJong argues that the concept of economic independence becomes meaningful as a health outcome for individuals with chronic disabling conditions.

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Preface

By Lex Frieden

The question is often asked, “What are the long- term goals of severely disabled people?” The answer is, more likely than not, that the goals of persons with severe disabilities are generally the same as those for anyone else. Most people want to have a family, a home, a car, a job, and recreational opportunities.

Some rehabilitation professionals, friends, and family members once discouraged persons with disabilities from adopting or seeking these goals. Severely disabled people were led to believe that these goals were unrealistic and impossible to reach and that they should be satisfied and happy to be alive. Little hope was given for disabled people to achieve near-normal lives. In fact, the general public’s expectations of life for people with disabilities could have been weighed on a different scale of normality from their own. What was considered a normal lifestyle for the general population was not considered normal for those with severe disabilities. As a result, many disabled persons adopted restricted goals and lowered expectations. Sometimes, even hope for a better life was buried so deep that it could not be resurrected.

During the late 1960s and early 1970s, a new concept related to rehabilitation and improvements in quality of life began to emerge and to be expressed by persons with disabilities. This concept, called Independent Living, was at first a reaction to repression. Some disabled people felt their lives were unnecessarily restricted by their disabilities. They acknowledged that barriers everyone faces to reach independence were further complicated by disability, but they believed those barriers could be overcome. They felt that supportive programs could be established and that environmental accommodations could be made to allow them to have opportunities and seek goals open to the general public. They rejected the notion, often expressed by professionals, that they should be confined to institutional care. They rejected the assumption that they had fewer rights than nondisabled people, and they rejected the idea that the government’s obligation to them was limited by their disability.

Persons with disabilities began to assert themselves in public forums. They organized and formed lobbying groups. They claimed equal rights as citizens to public services like transportation, housing, education and employment, and they demanded the right to vote. Although most of these rights were not denied intentionally or directly, they were indirectly denied by virtue of the fact that public transportation was inaccessible, as were housing, schools, businesses, public offices, and polls.

From the concept of independence, a movement emerged to overcome the barriers to a higher quality of life for disabled people. This movement was joined by disabled people, family members, friends, neighbors, politicians, opinion leaders, rehabilitation professionals, policymakers, and others throughout society. The movement led to new laws asserting equality and protecting the rights of disabled people. It led to new or adapted accommodations that made housing, transportation, public places, schools, and job sites accessible to persons with disabilities. It led to new, more positive attitudes by the general public toward persons with disabilities and to new attitudes of disabled people toward themselves. Perhaps most important of all, it led to new opportunities for severely disabled people to seek independence, to enjoy the benefits of their labors, and to enjoy the high standards and quality of life that society offers (Frieden, 1978)

As a result of the independent living (IL) movement and the changes that have occurred during the past few years, individuals with disabilities can now realistically seek goals that once were limited to those without disabilities. In fact, the limits imposed by severe disability may be

less important in determining the achievements of one's goals than certain other demographic and socioeconomic variables that are not related to a disability.

1. Independent Living (IL): Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, making decisions that lead to self-determination, and minimizing physical or psychological dependence on others (Frieden, Richards, Cole, & Bailey, 1979).

2. Independent Living Movement (IL): The process of translating into reality the theory that, given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals can actively participate in all aspects of society (Frieden et al., 1979)

3. Independent Living (IL) Program: A community- based program that has substantial consumer involvement. It provides direct or indirect services necessary to assist severely disabled individuals to increase self-determination and minimize unnecessary dependence on others (Frieden et al., 1979).

The principal barriers to achieving goals of independence may be categorized into three groups. They are environmental, personal, and economic. Environmental barriers are those that are independent of and beyond immediate control of the individual. Examples are curbs, steps, and narrow doorways. Personal barriers to independence relate directly to the individual and, more likely than not, can be changed. Personal barriers include negative attitudes, low self-esteem, feelings of dependence, unreasonable insecurity, unwillingness to take risks, preoccupations with cure, lack of ability to organize and plan, poor self-image, and unnecessarily limited expectations and goals. Economic barriers are those that relate to an inability to purchase needed equipment, supplies, and services.

Economic barriers may confound one's ability to overcome both environmental and personal barriers by restricting the range of possible solutions.

Solutions to overcoming barriers to independence exist now more than ever before. For overcoming environmental barriers, one may purchase or make adaptive equipment and devices. For example, high-level quadriplegics may purchase electrically powered wheelchairs controlled by slight movements of the chin or by sipping and puffing into a straw. Also available are sophisticated remote control devices and primitive robots. In addition to solutions that are customized and suitable for individuals, there are also more general and systematic solutions. These include mandated use of mass transportation vehicles made accessible by widening doorways, expanding seating areas, and installing ramps or lifts. They also include communitywide efforts to install ramps on curbs and to provide access to both public and private buildings. Solutions like these to overcoming environmental barriers are now widespread, and continued advocacy efforts are leading to more solutions each day.

With respect to personal barriers, there are several possible solutions. Rehabilitation counselors, psychologists, social workers, and other professional human service providers can help a person to analyze and overcome personal barriers. Peer counselors can share information, serve as role models, and provide necessary support. Family members and friends can give encouragement and help. Finally, on the personal level, self-determination, self-encouragement, self- control, and simply the passage of time can be instrumental in resolving personal barriers. On a broader scale, positive attitudes and expectations on the part of the general public, as well as realistic portrayals of disabled people by the mass media, would serve the same purpose.

Economic barriers may be the most difficult to overcome and the most important, since they can affect solutions to the other two types of barriers. Most people must depend on private and public insurance, private and public aid, and/or their own ability to work and earn money in order to overcome economic barriers. Independence costs more for disabled people than it does for nondisabled people, because, in addition to the normal expenses of housing, transportation, food, clothing and routine medical care, people with disabilities have expenses for adaptive equipment, medical supplies, and attendant care. The economic barriers to independence for disabled people are frequently complicated by the fact that in order to be independent, most people need a job. In order to have a job, however, they need to be reasonably independent.

Individual solutions to overcoming economic barriers are typified by the case of a person who receives housing subsidies to help pay for housing, vocational rehabilitation agency grants or subsidies help pay for educational or work-related expenses, welfare or human service agency subsidies to help pay for attendant expenses, and work income or Supplemental Security Income payments to cover the balance of other expenses. More general solutions to overcoming economic barriers may be legislated in the form of a nationalized health insurance program, a nationwide attendant care or home health care program, or the establishment of a nationwide system for purchase and distribution of equipment and devices for disabled people.

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During the past decade, a unique type of human service program has emerged to assist people with disabilities to reach their goals of independence. Independent living programs, which have been established since the independent living (IL) movement began and subscribe to the tenets of the IL philosophy, are located in at least one community in every state. Altogether, there are currently about 200 IL programs and service providers in the United States (Frieden & Veerkamp, 1984). These community-based programs are unique, because they are generally run by or managed in large part by consumers — disabled people themselves. They provide a variety of services, including housing referral, attendant care referral, information about goods and services provided by other agencies, peer counseling, transportation, equipment repair, independent living skills training, and advocacy. Their goal is to assist severely disabled people by increasing self-determination and minimizing unnecessary dependence on others.

In the early 1970s, IL programs were viewed as experiments in community living by severely disabled individuals. By 1978, these programs had demonstrated an unmatched ability to help disabled people live comparatively independent lives in their communities. As a result of their effectiveness, Public Law 95-602, the Rehabilitation Act Amendments of 1978, included a section (Title VII) authorizing federal support for IL programs. With this support, the independent living movement blossomed, and many new programs were established (Frieden, Widmer, & Richards, 1983). Although political and economic contingencies make the future of IL programs difficult to predict, there is no doubt that these programs have contributed to a "coming out" of severely disabled people all over the United States.

Independent living has developed as both a concept and a programmatic thrust affecting the lives of thousands of severely disabled people and many more family members, co-workers, and friends. Conceptually, independent living asserts that all who can should be encouraged to make important decisions that affect their own lives. The theory of independent living, however articulated, affirms every person's right to choose from among available options where to live, work, and worship; what to eat and wear; and with whom to associate. The theory also suggests that society has the responsibility to facilitate the independence of its disabled members by providing physical access to the environment and needed supportive services (Frieden, 1981).

The IL movement has made great progress helping society to recognize and meet its responsibility to facilitate independence by its disabled members. Many people who only a few years ago were living in their parents' homes or in institutions because of their disabilities are now living in the community. They are assuming responsibility for directing their own lives and making significant contributions to improving the quality of life for us all. Nevertheless, there are many thousands of disabled people who have yet to realize dreams of independence and self-determination. In order to help them reach their goals, it is necessary to continue developing new programs, explore new ways of facilitating independence, and address issues of policy, programming, and individual adjustment to disability.

Many important issues related to the concept of independent living and to the barriers that inhibit progress toward independence are discussed in the RTC/IL Monographs in Independent Living series. The multidisciplinary approach is vital to reach the kinds of synergistic and catalytic solutions needed to facilitate independence by those people who desire it. The third monograph, Economics and Independent Living, discusses how self-directed, nonmarket forms of productive activity are important sources of real economic independence. Also explored are cost-benefit and cost-effectiveness analyses as they relate to health care outcomes.

To those of us who are researchers or academicians, application of the concept of independence to people with disabilities is intellectually stimulating and challenging. To those of us who are practitioners in the field of rehabilitation or in other areas of human service, the idea of independent living by people with disabilities is imaginative and promising. Finally, to those of us who are disabled, independence is a goal that we be1ieve is justifiable and worth making great sacrifices to achieve.

Economics and Independent Living
By Gerben DeJong

One of the most highly valued forms of independence in our society is economic independence. This form of independence is so highly valued that it shapes a large proportion of public policy and private behavior. When we discuss the independent living aspirations of disabled Americans, we must not overlook the economic dimensions.

In this monograph, I shall argue that economic independence is, for most of us, so tenuous that it is largely a myth. However, I shall also argue that there are dimensions of economic independence that have not been fully grasped. Many of us, disabled people included, participate in many nonmarket forms of productive activity that contribute significantly to individual, family, and societal well being. It will be my contention that the self-directed nature of these productive activities constitutes an important, but not widely recognized, source of real economic independence.

In all of this we need to consider the role of economics as a discipline and as a profession that has been largely indifferent to the aspirations of disabled people as expressed in the independent living (IL) movement. Thus, another of my arguments is that conventional economic theory is part of a belief system with values and assumptions that differ from those espoused by the IL movement. As a result, the IL movement cannot count on conventional economics as a natural ally in furthering movement goals. Yet, ironically, as I hope to show, the independent living movement embraces many assumptions from economic theory as part of its own value system.

Like many other disciplines, economics is always expanding into new frontiers that have not been subjected to its peculiar form of analysis. Although economics has largely skirted disability issues, it is beginning to make significant inroads into one area that touches on the concerns of disabled people — the development of health care outcomes for use in cost benefit and cost-effectiveness analysis. These outcome measures will have much to say about the future of health and disability programs. But more threatening to disabled people is the fashion in which these outcomes may be used to measure, in economic terms, the value of human life itself. I take the position that the development of health care outcomes needs to take into account independent living values that are expressed by disabled people. After all, they are the ones who will be affected by these outcome measures. In so doing, I shall also consider how issues related to economic independence should be incorporated into the development of health care outcomes.

The Myth of Economic Independence

Economic independence is the avowed goal of many publicly supported social and economic programs. Explicitly or implicitly, program effectiveness is defined in terms of economic independence, i.e., being off welfare or being gainfully employed. For people with disabilities, the most obvious example is the “status 26 case closure” used in the federal-state vocational rehabilitation program to denote whether a client has been gainfully employed for a prescribed period of time. For nondisabled people, an obvious example would be the job placement goal used in the Work Incentive Program (WIN) targeted to those receiving assistance under the Aid to Families with Dependent Children (AFDC) Program. Moreover, many of our

income transfer programs have some type of feature to encourage recipients to seek gainful work.

There is a tendency to focus the issue of economic independence on the economically vulnerable — the person with a disability, the female single parent, and others. Yet, more and more of us who do not identify ourselves with such groups are becoming aware of our own economic vulnerability and dependence, especially during recessionary times. We begin to realize that we are not economically independent at all. Increasingly, we find ourselves confronted with economic realities that are beyond our control: an oil embargo, an air traffic controllers' strike, high interest rates, a reduced congressional appropriation, and other events that clearly tell us that we are not always masters of our own economic fate as the term economic independence suggests.

Economic independence is so illusory as to be a myth for all but a few. Our economic well being is dependent on many prior conditions over which we have no direct control. We as a society impose the norms of economic independence on the nation's most vulnerable citizenry while overlooking, if not denying, our own vulnerability. This self-deception, I believe, is rooted in our need to feel superior to other elements in society. Superiority gives us definition, self-esteem; it reassures us that we are not at the bottom of the heap. The concept of economic independence is used to separate one part of the social hierarchy from another. Thus, while many of us sense our economic vulnerability, we deny it. We perpetuate the myth of economic independence because it fuels our sense of self-worth. Is it any wonder, then, that so many of us would be devastated if we lost our jobs and our rung on the socioeconomic ladder to which we so desperately cling?

In fact, I would go further. I am prepared to suggest that many people do not want to see disabled people become economically independent. Because of deeply felt psychological needs, many nondisabled individuals have a vested interest in maintaining the economic dependence of disabled people. The economically independent disabled person is often too threatening. The implied message is clear: They (disabled people) might be like us (nondisabled people), and with that realization, our sense of social distance crumbles.

Nonmarket Economic Independence

As indicated above, economic independence is usually defined in terms of a person's ability to be gainfully employed, to be a wage earner, to receive compensation via the market economy. However, those of us who have worked side by side with disabled people know of the many unpaid contributions they make to family and community life. Historically, many disabled individuals have been prevented from receiving pay for what they do because of financial disincentives lodged in income transfer programs. Until the advent of the Social Security Disability Amendments of 1980, our most important disability-related income transfer programs inadvertently penalized disabled people with large benefit losses when they earned very modest amounts of income.

We need to recognize formally the many unpaid, nonmarket forms of productivity — in the home, in the community, among peers, and in other spheres — that enhance societal well being. We as a society are only beginning to recognize these productive activities. We are, for example, reluctantly beginning to place some value on the unpaid work of homemakers, perhaps out of deference to the women's movement, which has argued that women's work has always been undervalued and unappreciated. Even the federal-state vocational rehabilitation system now recognizes homemaking as a legitimate rehabilitation goal.

In this recent political era, with its nostalgic emphasis on the family (and when politicians are evaluated as to whether they are pro-family), we may see a convergence of political interests, from both the left and the right, that give increased recognition to unpaid work done on behalf of the family. In addition, the renewed emphasis on volunteerism may also kindle new interest in nonmarket forms of productivity. However, I sometimes suspect that much of the proposed unpaid volunteerism is intended to displace paid work, a development that would implicitly demean work that previously had been compensated.

One of the most insightful analyses of unpaid economic activity and productivity in recent years comes not from mainstream economics but from social historian and futurist, Alvin Toffler, in his book, *The Third Wave* (1980). Although one can quibble with parts of his analysis, I believe Toffler offers us a framework in which we can understand nonmarket activity and what economic independence might mean in the future for disabled and nondisabled alike.

According to Toffler, the economic history of the last 300 years or so can be divided into three phases or waves. Wave I was an agricultural economy in which people produced goods and services mainly for their own consumption. People worked in or near their homes and were largely self-sufficient. Wave II was the Industrial Revolution, in which people produced goods and services mainly for the consumption of others via the market. People worked away from their home and were largely dependent upon the viability of the market place. Wave III is the postindustrial economy, in which people once again produce for their own consumption. People are again beginning to work at home and learning to be self-sufficient.

Wave III is not a mere throwback to Wave I but reflects the emergence of new technologies and patterns of production that are not dependent on large-scale organizations. Much of the Wave III economy is the do-it-yourself, work-at-home economy. It is the individual who puts a new roof on his house, who takes her own child's throat culture, who works as a freelance computer software writer, who builds her own furniture, or to borrow an example from the field of independent living, works as a self-employed independent living service provider under contract to a state human service agency. Toffler observes that much of this development is, and will be, the result of new computer technology that makes on-site work unnecessary except for an occasional face-to-face meeting with colleagues or clients. The advent of electronic mail, word processing, and other technological advances also allows people to do much of their work at home.

To clarify things further, Toffler divides work into two sectors. Sector A work is unpaid work done by people for themselves, their families, and their communities. Sector B work is paid work done by people for sale or swap through an exchange network or the market. Toffler predicts that with the emergence of Wave III, we will see a renewed appreciation for Sector A type of work.

Toffler also cites the rise of the self-help movement as an indicator of the emerging Sector A economy. More and more people are turning away from helping professionals and relying instead on peers for guidance and support. Several examples are well known to most us us: former addicts, alcoholics, overeaters, gamblers, and others. The self-help movement is not limited to individuals with chronic behavior problems but also includes people who are trying to cope with the normal stresses of everyday living or who are trying to improve the quality of their lives (e.g., single parents, parents of newborns, widows, and men and women seeking consciousness-raising experiences of one kind or another). The independent living movement shares a special affinity with all these self-help movements. In fact, the IL movement is the self-help counterpart for persons with disabilities (DeJong, 1979a; 1979b)

According to Toffler (1980, pp.279-283), we may need to rethink many of the concepts in conventional economics (e.g., income, poverty, and unemployment). To illustrate, consider our usual measure of production and national productivity, the GNP. The definition of GNP may

be outdated, since productivity is still defined in terms of Sector B, i.e., that which is produced for the market economy:

There is no recognition as yet that actual production also takes place in Sector A — that goods and services produced for oneself are quite real, and that they displace or substitute for goods and services turned out in Sector B. Conventional production figures, especially GNP figures, will make less and less sense until we explicitly expand them to include what happens in Sector A.

To illustrate further, consider the income—leisure or work-leisure trade-off model used in conventional economic theory (Figure 1). The model assumes that a person receives utility from both income and leisure and will choose a combination of work and leisure depending on the wage rate. The model also assumes that a person is indifferent toward various combinations of income and leisure, as denoted by the declining marginal utility or indifference curves (Ii and 12). Thus, a loss of leisure (Ll-L2), i.e., more work, must be compensated by a gain in income (Y2-Yl) if the person is to remain equally well off. The amount of work and leisure a person chooses in response to an increase in wages is determined by the point (B) at which the slope of the indifference curve (12) is equal to the slope of the line denoting the new wage rate.

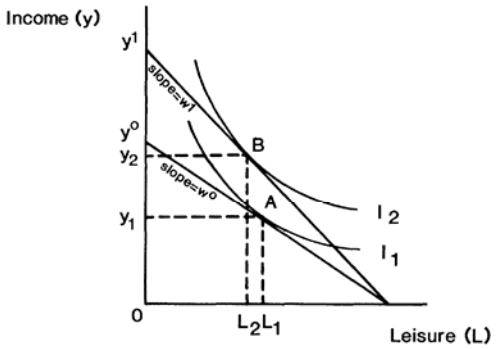

Figure 1: Income and leisure trade-off model.

The work-leisure model is often used in public finance theory to predict a person's response to changes in tax policy or to changes in income transfer policy (e.g., changes in "income disregards"), both of which effectively increase or decrease the de facto wage rate (i.e., after—tax income). But if Toffler's analysis is correct, the model may be obsolete in the sense that the real trade-off is not between work and leisure but between work in Sector B and Sector A. The welfare mother — whose work effort has been the subject of many studies — may not be choosing between work and leisure (as in conventional analysis) but between gainful work and "nongainful" work done in the home.' Likewise, the person with a disability may not be rejecting gainful work in Sector B (i.e., choosing leisure), but may instead be accepting work in Sector A that he or she believes will enhance his or her overall economic well-being. The sheer cost of specially adapted private transportation, for example, may not make it worthwhile, from an economic viewpoint, for a disabled person to work in Sector B. And conversely, the diminishing costs of new computer-assisted devices, for example, may make it more worthwhile from an economic standpoint, for a disabled person to work in Sector A.

(In all fairness to conventional economics, it should be mentioned that economists have indirectly considered Sector B activity in the theory of the household as a production unit. According to production theory, a household allocates its resources (money, time, energy) to maximize production (earned income, child care, food preparation, etc.). However, it is the income-leisure trade-off model that has dominated empirical research with respect to the economic behavior of welfare recipients.)

But more significantly, work in Sector A is inherently more self-directing, a quality that is also central to the philosophy of the independent living movement. Thus, more real independence may be found in the Sector A economy than in the Sector B economy. The flaw in Sector B is that independence and self-direction are often compromised by the demands of the market and the regimentation imposed by large-scale organizations.

True economic independence, then, is the ability to be self-directing in one's work. If Toffler is correct, Sector A offers greater opportunity for self-direction than Sector B does. Sector A offers freedom from the endless specialization, relentless standardization, mindless regulation, and hopeless alienation that has characterized industrial society and the market economy upon which work in Sector B is dependent.

The emerging Sector A economy does not yet provide full economic self-sufficiency for most people. Still, Sector A may provide disabled people opportunities for a measure of self-sufficiency that has historically been denied them in Sector B. There is much less discrimination in a self-directed enterprise than in a large-scale organization that has incorporated the prejudices of society at large.

I am not suggesting that individuals with disabilities ought to be relegated to small at-home cottage industries that isolate them from the mainstream of society and the market economy. However, I am suggesting that Sector A may provide for a measure of true economic independence and a measure of economic self- sufficiency not to be found in Sector B. And further, the reemergence of Sector A should not be shunned as demeaning or dismissed as part of a second-class economy.

Economics as a Discipline

Almost every discipline can be faulted for not keeping up with changing times. The fact that economic theory has not kept pace with changes noted by Toffler is not unique to economics. But I believe that there is something more fundamentally amiss. The questions I should like to set forth are these: Why has economics as a discipline failed to take the problem of disability seriously? Why are disability issues sometimes perceived as being beyond the scope of conventional economic analysis? Can conventional economic theory adequately respond to the aspirations of disabled people as articulated in the independent living movement?

One might respond to these questions by noting that disabled people are often not a part of the economic mainstream in our society and thus beyond the concerns of economics. However accurate this perception might be, I believe that the real answers are more indigenous to economic theory and analysis than they are to the absence of disabled people in the market economy of our nation.

It is impossible to critique a discipline or a profession fully within the scope of this monograph. Hence, I have elected to focus on just a few of the key assumptions and guiding forces that have shaped economic theory, as we know it today.

Neoclassical Theory

For almost a century, the leading school of economic theory has been the neoclassical school of economics, beginning with British economist Alfred Marshall (1842-1924). Despite numerous economic and social changes since, the models of economic behavior underlying neoclassical theory have endured to the present. The mastery of these models and their complex mathematical reasoning constitute the gateway through which one must pass in becoming a bona fide member of the economics profession. Much of the economics literature today consists of endless applications and variations of the theoretical models spawned by the neoclassical school. Neoclassical economics is more than a theory about consumption, production, and market equilibrium. Implicit in the neoclassical framework are value-laden assumptions that effectively limit the scope of social reality subjected to formal economic analysis. It is my contention that these assumptions also limit the economist's ability to respond adequately to many disability and independent living issues. My intent here is to identify these assumptions and explore how they

tend to preclude economists from adequately addressing the independent living aspirations of persons with disabilities.

In order to give my analysis some structure, I have organized my critique of neoclassical theory and disability under four main rubrics: (1) individualism and view of the community; (2) marginalism, optimization, equilibrium, and view of social change; (3) automation and view of government; and (4) value neutralism.

Individualism and view of the community. Neoclassical theory begins with certain assumptions about the nature of humans and their relationship to the larger society. It assumes that people are basically selfish, acquisitive, and act primarily in their own interests. Such self-interest is said to be rational:

Each individual seeks to maximize pleasure and minimize pain. This utilitarian principle is the cornerstone of modern consumer demand theory. In the parlance of neoclassical economics, each person seeks to maximize his or her utility. Given a choice between two commodities, X or Y, an individual will choose those quantities of X and Y that will maximize his or her utility, subject to the constraint of his or her income. This model of human behavior bears a strong resemblance to the income—leisure trade-off model cited earlier in our discussion. In fact, the income-leisure model is but one of many variations of the more basic consumer demand model described here.

In consumer demand theory, no value judgment can be made about the validity of each person's interest. Each consumer is sovereign. Each consumer is the best judge of his or her own interests; individual utility is a personal matter. The satisfaction that one individual receives cannot be compared to that received by another. In other words, interpersonal utility comparisons are not possible.

Individual self-interest is also the basis for determining societal well-being. Each person advances the community's interest by pursuing his or her own interests. Or put the other way around, the community's well being is seen as a mere aggregation of each individual member's well-being. Community well-being is maximized when the pleasure, happiness, or utility of the majority is maximized.

By insisting that the social goal of the social order is the maximization of pleasure for the majority, it becomes easy to overlook the special concerns of vulnerable minorities such as people with disabilities. Moreover, by refusing to make any value judgment about each individual's utility or preference function, neoclassical economics effectively precludes consideration or prior ethical issues that affect resource allocation and the well-being of disabled people.

Hence, neoclassical theory deprives disabled people of an intellectual justification for the consideration of their special needs. In fact, neoclassical theory is even more perverse by suggesting that the consideration of special needs would create disutility for the majority and thus compromise overall societal utility.

The fatal flaw in neoclassical reasoning is that it sees community well-being to be a function of individual well-being, but not the converse: that individual well-being is, in part, a function of community wellbeing. Neoclassical economics fails to see the community as something more than the sum of its individual parts; it does not recognize that there are secondary gains for both majority and minority members when the community's larger interests are considered.

To reject the individualism of neoclassical theory is not to reject the importance of the disabled individual or the importance of individual needs and differences. However, the well-being of the disabled individual is inseparable from the well-being of the community. The community is, after all, the larger environment in which the disabled person, and all of the rest of

us, must live. And as independent living theory so clearly states, it is the accessibility of that environment, the well-being of that community that determines the quality of life for a person with a disability. Thus, by focusing on the individual, neoclassical economics is bound to overlook those environmental and community factors affecting the disabled person's quality of life and sense of well-being, or in the parlance of neoclassical economics, his or her utility.

Marginalism, optimization, equilibrium, and view of social change. Neoclassical economics is largely concerned with "adjustments at the margin"— how marginal changes in one variable affect marginal changes in another. Or to state the matter more formally, neoclassical economics is concerned with the rate of change in the equilibrium value of an endogenous variable with respect to a rate of change in an exogenous variable. Hence, neoclassical economics lends itself to the use of differential calculus, which has helped to legitimize economics as a quantitative and mathematically rigorous discipline.

Even the casual observer of academic economics cannot help notice the many references to marginal analysis: marginal utility, marginal rate of substitution, marginal revenue, marginal product, marginal revenue product, etc. But marginal analysis is more than a form of academic inquiry. It is a belief system; hence, the term marginalism. Neoclassical theory insists that marginal adjustments are not only analytically interesting, but also optimal. Marginality and optimality are inseparable-—e.g., profit is maximized when marginal cost equals marginal revenue.

Marginalism is inherently conservative, since it makes no judgment about the existing economic and social structure. The existing system is taken as a given. The optimum position is always seen as some function of the status quo. This view is best observed in the concept of Pareto optimality, which is defined as a situation where a marginal change makes someone better off without making someone worse off.

Even when dealing with more than marginal social problems, economists still resort to marginal analysis. In the case of income inequality, for example, economists have used marginal analysis to justify income transfers. Economists argue that the marginal utility of an additional dollar given to a poor person is greater than the marginal disutility of the same dollar taken from a rich person. "This kind of reasoning stems from a desperate attempt to find a nonmoral arithmetical basis for a measure which can only be justified on moral grounds" (Weisskopf, 1971, p.99). In fact, this kind of reasoning could be reversed: In transferring a dollar of income from a rich person to a poor person, a rich miser's grief may be greater than a poor ascetic's happiness. As Weisskopf (1971, p.99) so aptly concludes: "This kind of intellectual acrobatics shows how far technical reasoning will go to avoid moral judgment."

The concepts of marginality and optimality are clearly related to the concept of equilibrium. All forces, according to neoclassical theory, are either at equilibrium or are moving toward a new equilibrium. Optimality is achieved at the point of equilibrium. It is the point at which consumer utility or producer profits are maximized. Marginal analysis is used to study the change from one equilibrium condition to another.

Neoclassical theory considers the equilibrium condition to be inherently good irrespective of under— lying economic and social disparities. As previously indicated, neoclassical theory implicitly sanctions the status quo. It provides the intellectual justification not to respond vigorously to the needs of groups such as the disabled. However, the independent living and disability rights movement is not calling for small incremental changes but is demanding a fundamentally new consciousness about how disabled people want to be viewed and how their needs should be addressed. The concepts of equilibrium and marginality will not suffice; nor is the status quo to be considered optimal. Economic and political reality may dictate incremental

political strategies, but the ultimate goal is a very different state of affairs from today's state of equilibrium.

Neoclassical economics embraces a particular view of social change that is not only marginal but also places a particular burden on the individual. By insisting on the Pareto criterion, any marginal disutility that may accrue to the nondisabled majority is a priori ruled out. Thus, the burden for change is on the individual, not society. But IL theory rejects this view of social change. Disabled people see the main barriers to independent living to be ultimately societal and environmental in scope. To place the onus always on the individual, as neoclassical theory implicitly does, is to blame the victim. Neoclassical theory is heavily weighted in the direction of no action or, at most, modest corrective action that will not fundamentally change the underlying equilibrium.

Automation and view of government. According to neoclassical theory, changes in equilibrium are automatic: The system is self-correcting. The invisible hand of the market automatically harmonizes the utility maximizers on the demand side of the market with the profit maximizers on the supply side of the market. Neoclassical theory denies the existence of market power and insists that the invisible hand is the ultimate regulator of the economic system.

Neoclassical theory distrusts government. The government that interferes least governs best. Government should not restrain the hidden hand; it should only make sure that the hidden hand is allowed to move unconstrained. The role of government is to remain neutral, not to choose sides. However, this passive view of government has not been shared by the independent living movement. The invisible hand has not done for disabled people what it has done for others. It does not guarantee access to the economic system. Thus, the independent living movement has had to turn to government to guarantee access in a variety of ways — through the removal of architectural barriers, through affirmative action, through the provision of timely services that enable a disabled person to live more productively.

Value neutralism. I have observed in this discussion that neoclassical theory makes no value judgments about individual preferences, either about the existing social structure or about the nature and direction of changes made in the system. These are accepted as givens and beyond the moral purview of the economist. Neoclassicists insist that their descriptions and analyses of the economy are value-free. But such a position overlooks the fact that individual utility, marginality, optimality, equilibrium, and automation are not only tools or assumptions of economic investigation but are also parts of a larger belief system or world view. These concepts are not merely descriptive and analytical but normative as well. They are ends as well as means. The goals of the system are not examined, but that does not make economic analysis a value-free enterprise— only a value-empty one.

For persons in the IL movement, moral and ethical issues cannot simply be put aside. Resource allocations involve prior moral and ethical considerations. For example, does not society acquire some prior moral obligation to provide for some minimum quality of life for people whose disabilities arise from collective decisions to develop new life-saving technologies? And, further, should these obligations not be made explicit even if they should reduce the marginal utility of some?

Perfect competition. Much, if not all, of neoclassical theory comes to focus in the model of a perfectly competitive market, a model that remains to this day the strictest construction of free market thinking. The perfectly competitive market is the vehicle by which individual self-interest is translated into aggregate social well-being. According to Ferguson (1969), the

perfectly competitive market is also the vehicle by which aggregate social well-being is maximized:

If the political organization of a society is such as to accord paramount importance to its individual members, social welfare, or the economic well-being of the society, will be maximized if every consumer, every firm, every industry, and every input market is perfectly competitive (p. 446). An understanding of the perfectly competitive market can give us some additional insight into the assumptions and values of neoclassical theory and how they relate to the independent living aspirations of disabled persons.

A market is said to be competitive when certain criteria are met. If all are met, then the market is considered to be "perfectly competitive." The criteria for a perfectly competitive market are these: 1) rational self-interest; 2) perfect knowledge of buyers and sellers of all present and future market conditions; 3) open access— ease of entry and exit into the market; 4) smallness — no buyer or seller sufficiently large to affect the price; and 5) undifferentiated products.

In this type of economy, all the tools of marginal analysis and optimization are fully applicable. Of course, these assumptions and conditions are never fully attained in the real world. Nonetheless, to the extent to which they are partially attained, it is felt that a sufficiently competitive situation exists in which individual self-interest is, over time, translated into aggregate social well-being. In cases where the criteria are severely violated, such as monopoly and oligopoly, it is usually held that these instances are isolated or necessary to the public interest, as in the case of public utilities.

Interestingly, neoclassical economics has always been sufficiently robust to find some analytic justification for the existing distribution of economic power. But before we evaluate perfect competition from the perspective of independent living, it is worth considering the political analogue of perfect competition in the theory of democratic pluralism where nearly identical assumptions apply.

Democratic Pluralism

Although monopoly, oligopoly, and other market models require that the assumptions of perfect competition be relaxed, these models or modifications do not pose a fundamental threat to neoclassical theory, since all the tools of marginal analysis — which are so central to the methodology of contemporary economics — are still applicable.

Additional adjustments have been made to the perfect competition model in the theory of countervailing power. According to this theory, large and highly structured industries are not a matter of special concern because ". . . private economic power begets the countervailing power of those who are subjected to it" (Galbraith, 1956:4). Countervailing powers tend to neutralize each other. Strong labor unions neutralize the power of oligopolistic industries; organized buyers neutralize powerful sellers.

> The result, then, is a kind of market equilibrium or invisible hand that harmonizes the interests of all. The harmonious whole is now simply made up of a few neutralized giants rather than numerous atomistically competitive small firms. (Hunt, 1972:156—157)

The countervailing power theory demonstrates the durability and adaptability of free market theory to a wide variety of market conditions.

According to the pluralist theory, the American political process is one in which competing interests organize into groups to pursue their own interests rationally by bargaining in the political marketplace. The market is governed by certain rules of "a procedural consensus." The rules of the political market constitute the assumptions of the pluralist model. One of the rules is that there be freedom of entry and exit into the political marketplace. The open access assumption requires that there be no single group capable of denying other groups their right to participate in the political process. In the pluralist model, power and control are sufficiently distributed to prevent any group from becoming dominant, an assumption closely related to the premise in perfect competition that no buyer or seller is sufficiently large to affect the price. When one group seeks to advance its position by forming coalitions with other groups, countervailing coalitions or forces are likely to develop.

Bargaining is to the political process what bidding is to the economic market. Because no group is sufficiently dominant in the bargaining process, the various parties must compromise. By moving to some compromise, the system tends over time to be Pareto-optimal: It will tend to make some groups better off without making others worse off. Pareto-optimality is not a second-best solution but the optimal solution. It constitutes the point of equilibrium— the point at which political and social harmony is achieved. Equilibrium is the embodiment of the public interest. In the pluralist system, the oscillations around a given issue are fairly narrow, always tending toward equilibrium. Changes are seldom drastic but tend to be incremental or marginal. Such a system is said to be self-regulating and inherently stable. The automatic and mechanistic character of both perfect competition and pluralism led Lowi (1969) to conclude that the "hidden hand of capitalistic ideology could clasp the hidden hand of pluralism, and the two could shake affirmatively" (p. 47).

The Perspective of the Independent Living Movement

From the perspective of the independent living movement, the single greatest flaw in the perfect competition-pluralist thesis is the open access assumption. Barriers to access abound, and most do not require elaboration here. However, an important barrier often overlooked by the IL movement is the economic one: Those who come to the political marketplace with disproportionate economic power usually have the intellectual and political dexterity with which to maintain, if not extend, their special advantages. The truth of the matter is that the IL movement does not have extensive economic resources with which to conduct sophisticated benefit-cost studies to demonstrate the merits of its approach to disability issues. Nor does it have the economic resources to place syndicated political advertisements in newspapers, as does Mobil Oil Company. Pluralism assumes that the political arena is economically neutral. It is not. Interest group politics are usually loaded in favor of well- heeled groups. As Schattschneider (1975) once so aptly pointed out: "The flaw in the pluralist heaven is that the heavenly chorus sings with a strong upper-class accent" (p. 34-35). Unfortunately, most disabled people do not sing with the same accent.

Both perfect competition and pluralism suffer from a basic inconsistency in their assumptions. The open access and rational self-interest assumptions are mutually exclusive. It is always in the interest of incumbent groups to prevent incipient competitors such as disabled people from entering the market. Hence, the market, whether it be economic or political, had an inherent tendency to be exclusionary where one set of groups seeks to set the terms for another. The exclusionary nature of the pluralist system also accounts for much of its conservatism responding to the needs of economically vulnerable groups. A pluralist system that oscillates within a few degrees of the point of equilibrium is not likely to tolerate large fluctuations in

political thought or ideology. Those already in the system have a vested interest in making sure that the equilibrium is not upset. Preexisting power relationships are reinforced through marginal changes.

As I have also indicated in the discussion of neoclassical economics and automation, pluralism's alleged neutrality of the political process extends to its conception of the state and government. The state is considered to be a neutral party to the competition and the bargaining. The task of the state is to insure often characterized disability politics in the past. The movement has been instrumental in developing new coalitions such as the American Coalition of Citizens with Disabilities (ACCD) and is gradually beginning to address the needs of new groups such as those with mental disabilities.

As the IL movement continues to struggle for recognition, there will be increased temptation to pay lip service to free market and pluralist assumptions, especially when a conservative administration is in power. The hidden hand of the free market has a remarkably seductive quality for neoclassicists and pluralists. It also has a remarkable ability to seduce those seeking to gain access to the mainstream of America's economic and political systems.

Neoclassical Economics in Perspective

Despite some of its inherent limitations, neoclassical theory has armed economists with important tools with which to evaluate a variety of economic behaviors. Neoclassical theory has survived 100 years and is still being refined. My purpose here is not to call for an end to neoclassical analysis but simply to indicate that neoclassical theory is also a belief system with values and assumptions that limit the scope of economic analysis and predispose the economist to look at problems in a particular way. In this section, I have observed how neoclassical values and assumptions diverge from or converge with those of the independent living movement. For example, neoclassical theory fails to affirm the importance of the community in affecting the well-being of disabled persons, it sanctions the status quo, it creates a preference for no intervention, and it fails to take into account prior moral and ethical considerations. Independent living theory, however, affirms certain neoclassical concepts such as consumer sovereignty and open access.

But more serious is the fact that economists have not taken the subject of disability seriously. The reasons for this are not limited to shortcomings inherent in neoclassical theory. The economics profession addressed issues such as racial discrimination and poverty when these issues were a major national concern about a decade or more ago. Perhaps the absence of disabled people from the mainstream of American economic life has caused economists to overlook the economic problems associated with disability. Or are disabled people, in fact, on the bottom of the economic and social hierarchy and thus beyond the scope of legitimate and serious research? I often suspect so, especially when I observe the low rate of federal funding for disability-related research or when I observe the low esteem with which many disability- related professions are regarded.

One major exception to this observation is the work of economists such as Berkowitz, Rubin, and so on of Rutgers University. This small group of economists and scholars has been studying the economic consequences of disability for many years, especially those economic consequences that show up in the federal budget such as income transfer payments.

If economists are ever going to take disability issues seriously, it will probably come through the back door of health economics. The truth of the matter is that chronic disease and disability are the major health problems of our time from the standpoint of health care utilization and costs. As economists develop new cost-containment strategies in health care, the economic

consequences of long-term disability cannot be ignored. In addition, economists are becoming involved in the development of new health care measures often used in conjunction with benefit-cost studies. The development of these measures and outcomes is the subject of the next section.

Economic Analysis of Health Care Outcomes

Over the last few decades, there have been many attempts to develop new measures of health and wellbeing. These measures are designed to (1) measure the general health or functional status of a target population or (2) determine retroactively or prospectively whether a particular intervention was, or will be, effective or cost-effective. Many of these measures are not only measures of health status but are also measures of disability status.

The review of all of these measures is clearly beyond the scope of this monograph. My purpose here is two-fold. First, I wish to consider some of the normative issues involved in the economic analysis of health care outcomes — and for that matter, disability outcomes. Second, I want to consider how the economic analysis of health care outcomes can be more responsive to the issue of independence for people with disabilities. It concerns me that much of the debate on health and disability outcomes does not adequately reflect the concerns of those most directly involved, i.e., people with disabilities.

The emergence of economic analysis of health care outcomes occurs at a critical juncture in Western medical science. In recent years, we have seen a growing population of severely disabled people who owe their lives to new medical interventions and emergency care systems. A classic example would be the ventilator-dependent person with spinal-cord injuries who simply did not survive in any substantial numbers a few years ago. We immediately begin to ask what the quality of life is for such an individual and begin to wonder about the costs of maintaining such a life. I am deeply concerned that the use of existing outcome criteria may be heavily stacked against such individuals and that we may have to consider dimensions of independence and well-being that up until now may have been left unexplored.

The economic analysis of health care outcomes generally falls into two broad categories: (1) benefit-cost analysis and (2) cost-effectiveness analysis. The distinction between these two types of analysis is well-known to many and does not require extensive elaboration here except, perhaps, to make the following point:

The key distinction is that a benefit-cost analysis must value all outcomes (e.g., dollar) terms, including lives or years of life and morbidity, whereas a cost-effectiveness analysis serves to place priorities on alternative expenditures without requiring that the dollar value of life and health be assessed (Weinstein & Stason, 1977).

Another way of making this distinction is that in benefit-cost analysis both the numerator (benefits) and the denominator (costs) are expressed in monetary terms. But in cost-effectiveness analysis, only the denominator (costs) is expressed in monetary terms, while the numerator (effectiveness) is expressed in nonmonetary terms such as lives saved, deaths averted, gain in self-care skills, bed-free days, or some other unit of effectiveness. I shall refer here to both types of cost analysis, either together or individually. The context should make clear which is intended. In public life we pay great lip service to benefit-cost analysis as the criterion upon which we should allocate public resources. Yet, benefit-cost analysis is replete with methodological difficulties, as, for example, in the choice of discount rate to evaluate a future stream of benefits or costs. The greatest difficulty with benefit-cost analysis is its roots in the neoclassical theory of utility maximization discussed earlier: the maximization of pleasure (benefits) and the minimization of pain (costs) for all those affected. The problem is that pleasure (benefits) and

pain (costs) are seldom distributed equitably. What may be efficient — that is, maximizing the benefit-cost ratio--may not be equitable.

The issue of equity is most apparent in the attempt to measure future benefits such as the value of lives saved or lives kept free from disability. But often the value of a life is determined by a person's productive capacity as measured by his or her potential earnings. Aside from the fact that the concept of potential earnings is in itself an elusive concept, it raises enormous equity issues: Should the lives of men be valued more than the lives of women? The young more than the old? White more than black? Nondisabled more than disabled?

Cost-effectiveness analysis has attempted to work around these problems by not assigning a monetary value to each life saved. But as we know, the mere saving of life does not guarantee the quality of life that follows. Many (e.g., Pliskin, Shepherd, & Weinstein, 1980; Weinstein & Statson, 1977) have proposed the concept of "quality adjusted life years" (QALYs). This concept conveys the simple idea that a healthy year of life should be valued more than a nonhealthy year of life.

But how should a nonhealthy year be compared to a healthy year? For economists, the answer lies in utility theory. Given a choice between quality of life and length of life, an individual will be willing to give up a certain amount of longevity for a number of guaranteed healthy years as illustrated by the indifference curve mapped in Figure 2. A classic example of this choice is whether to undergo coronary bypass surgery, which offers relief from pain (angina) but also offers uncertain, if not reduced, longevity, including the risk of death during surgery. The use of utility or preference functions has also been suggested for the development of health status indices. Patrick, Bush, and Chen (1973) illustrate how a health status index might be developed based on trade-offs between variables such as (1) the ability to travel from one's residence, (2) the ability to ambulate, (3) the ability to conduct major and minor life activities such as self-care, and (4) freedom from symptoms (e.g., pain, visual problems, paralysis). Others (e.g., Torrance, Thomas, & Sackett, no date) have suggested that trade-offs can be made between diminished health in one period of remaining life with diminished health in another period of remaining life.

All of these suggested techniques draw on utility theory in one fashion or another. They illustrate how pervasive utility theory has become as an analytic technique that reaches well beyond the field of economics. Although no value judgment can be made about each person's utility function, utility theory does force us to consider some of the real trade-offs that formerly had been ignored.

However, from the perspective of the IL movement, several problems remain. The first problem is the issue of whose utility function should be considered normative in developing a health status index or outcome measure. The professional evaluator's? The provider's? The individual patient's? The taxpayer footing the bill? The IL movement would argue that the values of those most directly affected should be represented in the development of utility functions used to create a health status index.

The second problem is the issue of what criteria or what set of trade-offs should be incorporated into the formulation of a preference function or a health status index. From the perspective of the IL movement, quality of life is more than the ability to ambulate, the ability to be independent in self-care, or the absence of pain. In fact, for many disabled individuals, such criteria would represent a very low quality of life. The key issue for the IL movement is the extent to which an individual retains control over the decisions affecting his or her life. It is

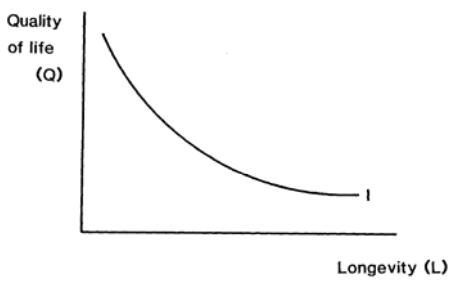

Figure 2: Quality of life and longevity trade-off model.

the extent to which an individual can be independent and self- directed. The critical issue is not whether a disabled person is dependent on human assistance in everyday activities, but rather, whether he or she is independent in the direction of that assistance. It is fair to say that this dimension of the quality of life has been largely overlooked in the development and analysis of health outcomes. Another approach used by economists (e.g., Thompson, Read, & Liang, 1981) to value life is the "willingness-to-pay" concept. This concept is basically another way of gauging a person's utility function by asking each person what he or she would be willing to pay to avert the risk of having a particular disease or disability. But this approach also has its limitations. First, willingness-to-pay favors those with greater ability to pay. Second, willingness-to-pay is biased against interventions or conditions in which an individual has little or no stake. Self-interest requires that individuals oppose programs that may not benefit them, even though they may benefit a significant minority of other individuals.

My point in all of this is that the appearance of rationality in the economic analysis of health care outcomes masks important philosophical and moral issues. The development of outcome measures to be used in benefit-cost and cost-effectiveness analysis may create preferences and have distributional impacts similar to those observed in our discussion on neoclassical economic theory.

Moreover, there are many prior moral and ethical questions that need to be addressed. Some analysts are fond of saying that health outcome measures and economic analyses are not a substitute for moral judgment. Still, because of their presumed objectivity, we ascribe great importance to the methods used to develop and evaluate health care outcomes. While it is not my intent to invoke all kinds of moral and ethical principles, I do believe that the independent living movement raises a number of prior issues relevant to the creation and analysis of health outcomes. I have already cited two prior concerns: (1) the involvement of disabled people in the development of health indices and (2) the consideration of independence and self-direction as dimensions critical to a person's quality of life. To this list, I wish to add a third issue that relates back to the discussion on Sector A productivity — productive activities outside the formal marketplace. People with disabilities have consistently argued that this dimension needs to be formally recognized by our various health and social programs. By not recognizing these activities we implicitly devalue them, and in so doing, we also devalue the lives of persons with disabilities.

Still, compared to other health and human service programs, independent living programs have been given considerable scrutiny — especially considering the very limited amount of funding that has been involved to date. Because the rise of independent living programs followed the rise of human service expenditures in the early 1970s, its claim to new public resources was much more visible and thus subjected to much more scrutiny than similar community-based programs in other sectors in the human services industry.

Conclusion

The future of economics with respect to independent living is uncertain. However, given the political and economic climate of the l980s, a few trends can be anticipated.

The first trend is the use of economic analysis in the evaluation of independent living programs. Many of these programs are now well beyond the demonstration stage which often made programs exempt from all but cursory scrutiny. Pressure will mount for independent living program to formally demonstrate their cost-effectiveness.

The second trend is the use of economic analysis in evaluating the overall cost of disability, not only in the form of income transfer payments but especially in the form of medical

care costs. With increasing emphasis on new cost containment strategies in medical care (especially hospitalization), economists and others will eventually target their concerns on the high—cost users of medical care, i.e., people with chronic disease and disabilities. Sooner or later, as longevity increases, chronic disease and disability will be the premier health and economic issue.

The third trend is the use of economic analysis in health care outcomes, a trend that was discussed earlier. This trend will continue to intensify especially as the field of health economics continues to grow and as evaluators intensify their search for meaningful outcome measures. Unfortunately, economic analysis, like any other form of analysis, is only as good as the assumptions upon which it is based. Sometimes these assumptions conform to the real world; at other times they have had to be relaxed to avoid serious analytic distortions. But more serious is the fact that economic assumptions are heavily value-laden and, as such, sometimes predispose the analysis in directions that fail to be responsive to the independent living goals of people with disabilities. The IL movement is not academically constituted to tackle more than 100 years of economic thought. But as new trends in the economic analysis of disability issues emerge, it will be up to individuals with disabilities to demand that economic analyses affecting their well-being take into account their views with respect to independence and quality of life.

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Commentary

By Alan M. Jette

DeJong presents a very thoughtful and at times provocative discussion of the interplay of traditional assumptions and theories from the discipline of economics with the relatively new independent living movement. I shall focus my brief comments on what I view as DeJong's major thesis: There are many economists who have only recently become interested in cost-benefit and cost-effectiveness analysis relative to outcomes of providing health care. In their efforts to evaluate the impact of modern health care provision systematically, they are at considerable risk, if not already guilty, of neglecting the important dimension of economic independence.

Drawing upon his extensive background in the independent living movement and the recent writings of social historian Alvin Toffler, DeJong presents a convincing argument that economic independence, if broadly defined, is as important, and in some circumstances more important, than more traditional health outcomes such as performance of basic daily living activities. DeJong asserts that true economic independence, which he defines as the ability to be self-directing in one's work, can be sought and achieved through two types of work: paid work done by people for sale or swap (what Toffler labels Sector B work) and unpaid work done by people for themselves, their families, or community (Sector A work). It is in this broader sense, DeJong argues, that the concept of economic independence becomes meaningful as a health outcome for individuals with chronic disabling conditions. I agree with De Jong's basic thesis. It would be strengthened, however, by a fuller review and critique of the shortcomings of existing health status indicators. Without this information, the reader who is unfamiliar with the health status literature is unable to make a full evaluation.

The concept of economic independence also needs further definition before it can be successfully incorporated into the development of future health status indices — the foundation stone of all economic analyses of health care outcomes. In its current form, it would prove most difficult to put into operation.

To illustrate this point, I shall briefly examine the two categories of work discussed in the monograph. Work done by people for sale or swap obviously contributes to one's economic independence and needs little discussion or elaboration. Traditional employment in the public or private sectors of our society or exchanging services or goods for other services or goods through a barter network are both examples of this category of unpaid work. In contrast, it is my belief that only certain types of work done by people without pay or exchange (Sector A work) can be appropriately considered under the rubric of economic independence. Here is where we need an elaboration of the concept of economic independence. To be included in the category of economic independence, as I interpret DeJong's position, work should contribute to the satisfaction of one's material needs. Sector A work that does not contribute to meeting one's material needs, while important in other ways, does not contribute to one's economic

independence. Thus, it would appear that only certain types of Sector A work, i.e., types that contributed toward meeting material needs, would fit the concept of independence. A few examples might illustrate the distinction.

Putting a new roof on one's house, growing one's own food, and participating in a food cooperative are all examples of Sector A work that contribute to satisfying one's material needs while minimizing the control of others. Yet, it is less clear to me how other types of unpaid work, for, example, being a volunteer in a local hospital or nursing home, contribute to the goal of economic independence. Activities of this nature seem to be directed toward non-economic ends and thus should not be included under the concept of economic independence. This type of Sector A work, while enhancing societal well-being, does not directly contribute to one's economic independence.

A more useful definition of economic independence, therefore, would allow us to distinguish Sector A work that contributes to economic ends from that which does not. Economic independence might alternatively be defined as the ability (through paid and unpaid activity) to satisfy one's own material needs free from the control of another. Such a definition would include Sector A as well as Sector B types of work, yet more clearly defines the boundaries of what is economically oriented work. If an activity contributed to one's own or one's family's material needs, it would contribute to economic independence; otherwise it would not.

I am sympathetic with DeJong's thesis that a fair and complete analysis of health care outcomes, especially with respect to individuals with chronic disabling conditions, must employ broader health status indices that advance beyond the traditionally narrow and overly restrictive emphasis on basic physical activity. Analysts of the provision of health care services must keep pace with advances being made in rehabilitation and related fields where the focus is no longer restricted to the correction or amelioration of physical impairment or disease pathology.

Movements such as the independent living movement are helping health professionals redirect their attention to the wide range of outcomes desired by patients. Concepts such as economic independence must be incorporated into the analysis of health care outcomes if future health policy is ever to be materially affected. DeJong has provided a valuable service by highlighting current deficiencies and for suggesting fruitful avenues for future research.