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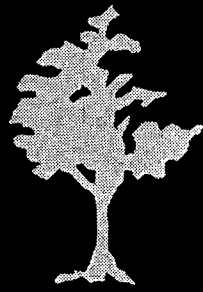
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RTC/IL MONOGRAPHS IN INDEPENDENT LIVING

Economics and Independent Living

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Economics and Independent Living

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PREFACE

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 Living¹, 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 movement² 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.

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 to 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.

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,³ 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 depen-

dence 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 believe is justifiable and worth making great sacrifices to achieve.

Lex Frieden

Footnotes

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).

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ECONOMICS AND INDEPENDENT LIVING

by Gerben DeJong

Economics and Independent Living

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 of 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 (I1 and I2). Thus, a loss of leisure (L1-L2), i.e., more work, must be compensated by a gain in income (Y2-Y1) 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 (I2) is equal to the slope of the line denoting the new wage rate (W1).

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

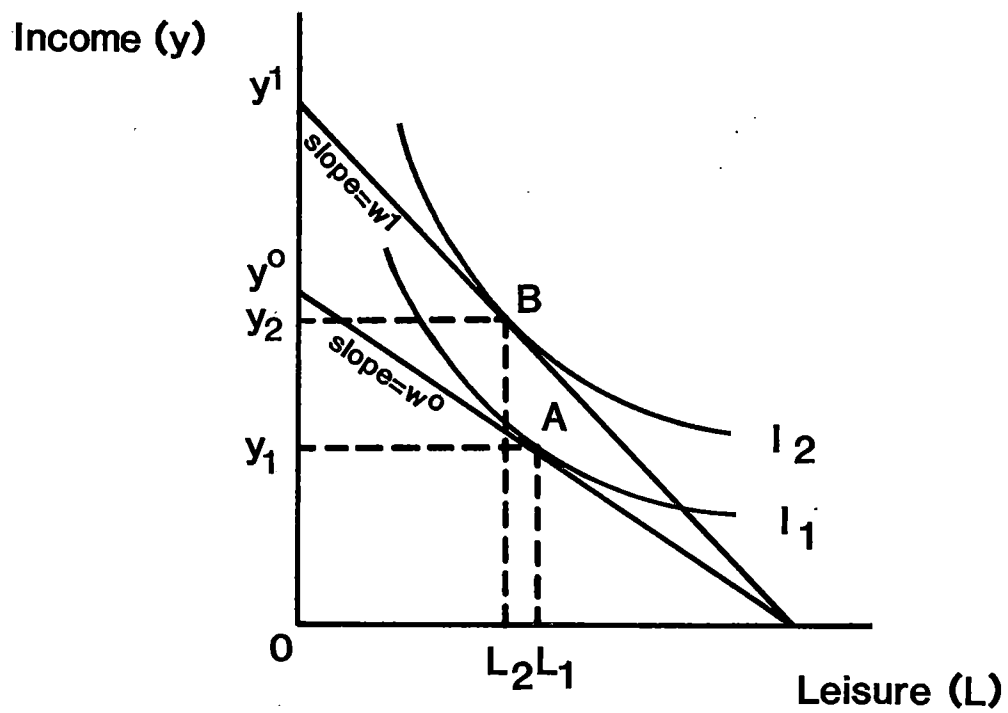


Figure 1: Income and leisure trade-off model.

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.¹ 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.

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

¹In 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.

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. Neo-classical 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, neo-classical 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 well-being. 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 underlying 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 neo-classical 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.²

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

According to the pluralist theory, the American political process is one in which competing interests organize into groups to pursue their own interests

²Although 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.

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. Pre-existing 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

the harmonic function of the system and to keep the system in good repair during periods of stress. However, those in the IL movement sometimes perceive the state as having a different role. The role of the state is not always seen as one of neutrality but as one of stability in an effort to maintain vested interests and pre-existing power relationships.

Despite the fact that disabled people as a group have been excluded from the mainstream of this nation's economic and political system, the independent living movement has often been an apologist for many neoclassical-pluralist principles. It would seem strange for the IL movement to be an apologist for a system that has excluded them. The fact of the matter is that while disabled people have been excluded from full participation in the American economic-political system, they still subscribe to the system's most cherished values and assumptions. They still want to be part of the system.

Take, for example, the economic doctrine of consumer sovereignty. This doctrine embraces the rational self-interest and perfect knowledge assumptions of the perfectly competitive market and asserts that it is the consumer, and not the provider, who should ultimately determine what goods and services should be made available in a free market system. Consumer sovereignty, sometimes referred to as "consumer involvement," is now enshrined in the movement for independent living. The doctrine clearly asserts that because disabled persons are the best judges of their own interests, they should have a larger voice in determining what services are provided in the disability services market.

The search for an alternative service delivery system also reflects the movement's commitment to important free market values. The development of independent living service centers has sometimes been justified as a way of making the delivery of human services more competitive. The establishment of non-profit consumer-directed service organizations is said to help break the stranglehold of state-controlled human service organizations such as public welfare departments or vocational rehabilitation agencies. Such rhetoric speaks to the open access and smallness assumptions of the perfectly competitive market.

In like manner, the movement for independent living subscribes to the assumptions of the pluralist theory by seeking full access to the political arena. In this case, the political arena is not a formal legislative body but the constellation of supporting and competing interest groups that help to shape disability policy--providers, professionals, disability organizations, legislative committees, and executive agencies.

However, the IL movement's support for the perfect competition-pluralist value system is not an unqualified one, as I have observed earlier. Moreover, there are several features of the IL movement that will help to mitigate some of the more destructive characteristics of the neoclassical-pluralist thesis.

First, the movement has steered away from destructive individualism. It has encouraged community support and mutual responsibility. The emphasis on self-help and self-reliance has a communal as well as an individual component.

Second, the movement has helped to foster a sense of self-worth that cannot always be obtained in the competitive market. In the competitive market, as I have pointed out, one's labor is often reduced to a commodity to be bought and sold like other means of production. The competitive market often becomes the standard by which individuals measure their own self-worth. Because the competitive market has often excluded disabled people, the movement has discounted the competitive market as the sole standard of self-worth. Instead, the movement has worked hard to promote self-esteem through community action and support.

Third, the movement has insisted that the pathology is in the environment, not the individual. In the neoclassical conception, the problem is implicitly defined as a failure of self-reliance. The movement argues, for example, that the failure to be gainfully employed does not necessarily rest with the individual but with the market, which has been unable to make useful work available or accessible.

And, fourth, the movement has, in some instances, turned away from the destructive competition that has

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 well-being. 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 norma-

tive 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 util-

ity 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,

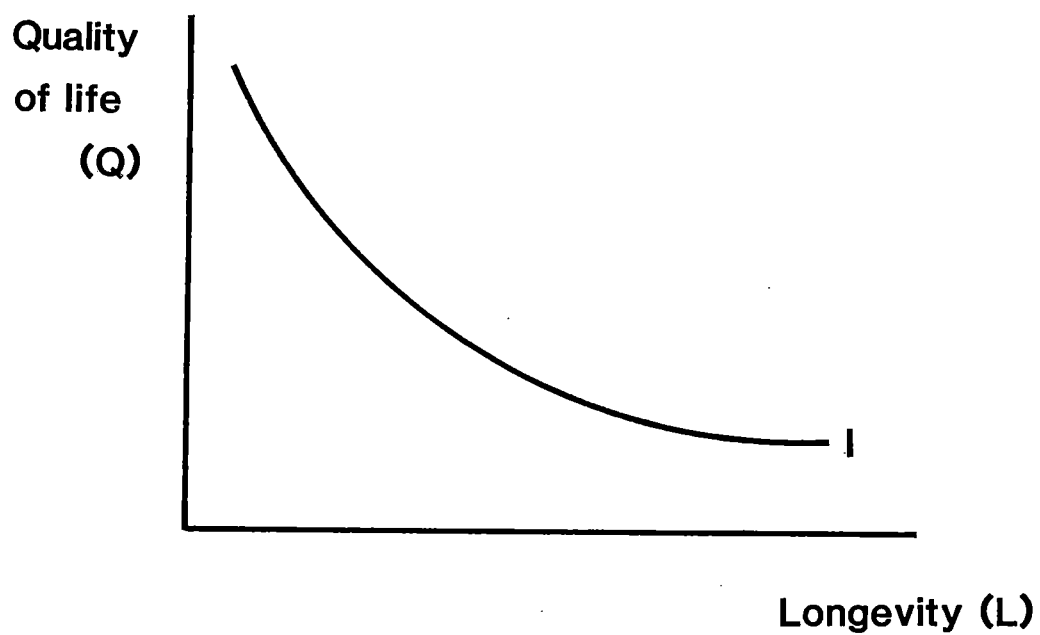


Figure 2: Quality of life and longevity trade-off model.

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 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.

Conclusion

The future of economics with respect to independent living is uncertain. However, given the political and economic climate of the 1980s, 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 programs to formally demonstrate their cost-effectiveness.³

The second trend is the use of economic analysis in evaluating the overall cost of disability, not only

³Still, 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.

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 DeJong'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 contri-

butes 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.



RTC/IL MONOGRAPHS IN INDEPENDENT LIVING

**A Social
Psychological
Perspective**

Frederick X. Gibbons

A Social Psychological Perspective

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PREFACE

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 Living¹, 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 movement² 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.

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 to 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.

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,³ 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 depen-

dence 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. This second monograph, A Social Psychological Perspective, uses innovative psychological research on independence and mental and physical health to extend and clarify independent living philosophy.

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 believe is justifiable and worth making great sacrifices to achieve.

Lex Frieden

Footnotes

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).

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A Social Psychological Perspective

by Frederick X. Gibbons

In a chapter on social attitudes among white and minority children, David Rosenfield and Walter Stephan (1981) suggested that forced integration is "America's most important social experiment." They say this because of the way racial desegregation and integration were implemented in this country, especially busing. For the most part, the procedure has been to initiate a new policy and then find out whether it is effective and what effects it has on the children who are participating in the change. In many respects, the independence as well as the normalization movements among persons with disabilities have developed in a similar manner. Like integration, they are also social programs that have been instituted quickly in an attempt to improve an unacceptable social situation. Like busing, they are also social experiments that can and will have a tremendous impact on those involved in them.

The learn-from-experience approach to social programs causes difficulties for service consumers and confusion for service providers. Nevertheless, as was the case with many black leaders and student activists in the 1960s and early 1970s, the message presented by many disabled persons is clear. They want independence--as much and as soon as possible--and they are not willing to adopt a wait-and-see attitude while social scientists or policy planners experiment with conservative implementation methods. The programs are here, they will continue to increase in number, and they are going to affect thousands of persons and cost millions of dollars. In the meantime, it is essential that we direct some of our attention to program evaluation. What we have in the independent living movement is a social experiment of tremendous importance but little or no data to either understand how it works or evaluate its effectiveness. I want to argue here that if we take an empirical look at social interaction within the independent living (IL) movement, we may be able to see how these programs function and, therefore, how they might be validated and improved.

In this second monograph in the RTC/IL Monographs in Independent Living series, I examine the social experiment of independent living from an experimental social psychological perspective. I touch on a number of divergent but related topics. First, there is the relevant theoretical work that emphasizes the basic human need for independence. This is the fundamental

postulate of my argument. At the same time, there are important individual differences in this general need and problems that are likely to be produced by the movement. Finally, there is the research, some that has already been done and some that still needs to be done, to provide information on how some of the inevitable problems might be met. Throughout the monograph, evidence from the literature is discussed to suggest what kind of an effect independence and the freedom that comes with it are likely to have on those who are directly and vicariously involved in the independent living movement. Although very little of this research is concerned specifically with independence per se, it is all applicable to this topic and the issues that are a part of it. The first such issue is the most basic: the need for independence.

Perceptions of Independence and Health

The concept of behavioral independence is something psychologists have been examining for quite some time. There has been a definite resurgence of interest in the last 6 or 7 years, due, in large part, to the pioneering work of Martin Seligman (1975) and others in the areas of learning and clinical psychology. At the same time, there has been renewed interest among social psychologists in a related topic--the concept of control.

As defined by psychologists, control refers to the ability to determine, at a very basic level, what happens to us--in other words, the ability to affect our environment, including the persons in it, while it, in turn, affects us. This concept of control is really at the heart of the independence movement. To live independently means having as much control over one's life as one is capable of having. In this respect, independence can be thought of as the freedom to make fundamental behavioral decisions that have immediate and long-term effects on the direction of one's own life. One such freedom, and it is an important one, is the right to determine how much independence one wants.

Perhaps the best way to illustrate the importance of this concept is to talk about what happens when we believe we do not have control over our lives. There is a strong relationship between the recognition of per-

sonal control and mental health. In particular, it appears that perceived loss of control is very disturbing and can lead to severe psychological and physical problems. Mildly depressed people, for example, often feel that they are losing control over their environment. In other words, they feel that what they are doing is having very little influence over what happens to them. Typically, this process occurs gradually--sometimes over a period of years--with seemingly minor events (such as a poor grade or failure to get a promotion at work) having cumulative effects. If the process continues unchecked, the person can enter what Seligman has called a state of learned helplessness, which is characterized primarily by severe depression together with a surrendering of all hope of regaining control.

Helplessness occurs as a result of frustration. What usually happens is that the person tries repeatedly to reach some goal or change some behavior, but to no avail. Trial after unsuccessful trial eventually leads the individual to the conclusion, "There is nothing I can do to help myself, so why bother?" Worse yet, repeated failure at one (important) task can lead to a generalized state of resignation in which the person stops trying altogether. The helpless individual may stop caring for him or herself and become physically ill. This is a very severe psychological state, which, fortunately, does not appear to be common. However, laboratory research has indicated that milder forms of the same psychological state are quite common and are also associated with a general decline in motivation and effort and various types of psychogenic illnesses (e.g., Pennebaker, 1982).

Control and Effort

Some examples from the research literature might help clarify this point and further define the concept of control. Carol Dweck (1978) has demonstrated in her work with nondisabled children that they will manifest mild symptoms of helplessness in response to certain types of attributional feedback (i.e., explanations for behavior) from their teachers. For example, when their failures at cognitive or artistic tasks are consistently attributed to low ability, children are likely to start believing that their efforts are not going to

make much of a difference and, therefore, that their outcomes are uncontrollable. When this happens, they lose what psychologists call a sense of effectance, or the feeling that they are doing something and getting something accomplished. As a consequence, their subsequent performance declines, sometimes drastically. In contrast, when children are told that their failure is due to insufficient effort (rather than the fact that they have no ability), the message to them is that improvement and success are possible, given their level of ability, if they will continue to try. Under these circumstances, they are very likely to increase their efforts and improve. In general, the more children or adults are led to believe that they can control their environment and what happens to them, the more they will actually try to exert control. However, if they perceive that they do not have the ability to affect the contingency between behavior and outcome, their motivation will decline, and some will eventually give up.

It is important to point out here that it is the person's perception or subjective impression of how much control he or she has that determines how much effort to exert. It is quite possible that a teacher or staff member may believe that a particular child or client is almost totally helpless, whereas the individual feels otherwise. For some people, control over simple day-to-day activities may be sufficient to keep their motivation level up, while for others even this basic level of control may not be considered necessary or important. Thus, a feeling of control at some level is essential for mental health, but that level can vary, sometimes, considerably, from one person to the next. In fact, individual differences in needs for independence and reactions to it constitute an important topic with many implications for service delivery.

Control and Disabled Persons

Work (similar to that of Carol Dweck's) by John Weisz with a disabled population has produced comparable results. He found that mentally retarded children, like nonretarded children, will drastically reduce their efforts if they are told that they have not done well on some task because they do not have much ability. They will also increase their efforts,

if they are led to believe that they do have control (ability) but have not exerted it enough. Unfortunately, Weisz also found evidence that this was not always the case among older retarded children. Adolescents behaved in a manner that reflected feelings of learned helplessness, but only after they had failed. Reactions to failure are particularly important. As Weisz (1979; 1981) suggests, years of experience with feedback indicating that failure is due to uncontrollable factors, primarily low ability, can seriously damage the child's motivation and cause the child to feel that further effort is pointless. After all (from the child's perspective), why try if others, especially teachers, are telling you that it doesn't make any difference anyway? Once this point has been reached, the child--like the adult, for that matter--will become much more dependent on others, and learning will become difficult if not impossible. Moreover, the damage takes a long time to repair, and considerable effort may be required to convince the person once again that more effort can result in success. What all of this suggests, then, is that teachers and others working with children who are disabled need to pay attention to the feedback they provide. Every attempt should be made to avoid the long-term debilitating effect that low ability attributions can have on motivation. Attention should be focused instead on what is possible through increased effort. Moreover, environments should be structured so that long-term low ability attributions can be replaced with others more likely to promote effort.

Perhaps the most dramatic demonstration of the influence of behavioral control on mental and physical health can be found in a series of studies with older persons by Langer and Rodin (1976) and by Schulz and Hanusa (1978). They examined the effects of a very simple intervention to increase feelings of perceived control among several groups of nursing home residents by assigning more responsibility to them. Experimental subjects in the research by Langer and Rodin (1976) heard a talk by staff members that placed considerable emphasis on the amount of independence the residents had and on the fact that they were the ones who were primarily responsible for their own well-being. The talk heard by the control group suggested that staff members were the ones who were responsible for resi-

dents' care. There was one other manipulation--again, a simple one: Experimental subjects were given a house plant that they were supposed to care for, whereas control subjects' plants were tended by the staff. As basic as this intervention may seem, it had impressive results. The self-responsible group reported that they were happier than the other-responsible residents, and they were rated by the staff as more sociable and more vigorous. However, the most impressive finding was that a follow-up analysis revealed that the latter group actually lived significantly longer than did the low-control group!

Many ILCs practice a similar type of control intervention in which consumers are given some say about the services they receive. This may range from some simple participation in the decision as to when and where attendant care is provided up to allocating funds to individuals so they can arrange for payment of their own care or services. Arrangements of this type do foster a sense of control or effectance among clients of ILCs as well as nursing homes and institutions and are likely to promote adjustment and mental health. Moreover, these interventions tend to be easy to implement and relatively cost-effective, because the consumer takes responsibility for the supervision and coordination of his or her own services and also because the consumer can tailor the services to his or her own needs. This reduces duplication and waste. In general, with some constraints (see below), the more control consumers have, the more independent they are likely to feel and the more adaptable they will be.

A word of caution has been given by Schulz and Hanusa (1978). They conducted a similar intervention with nursing home residents in which residents were given control over visiting schedules of student volunteers. There was evidence of significant improvement in psychological outlook within the experimental group. But several months after the intervention had been terminated, the high-control group had shown more psychological decline than had the no-control group. In other words, gaining some control over this seemingly trivial aspect of their lives and then losing it seemed to have a devastating effect on them.

Schulz and Hanusa suggest that long-term effects of the intervention were not favorable, because

participants may not have believed they actually had been given control over this aspect of their lives. Instead, they believed that control really remained with the administration, because administrators were responsible for initiation and termination of the intervention itself. In a sense, this may have caused the process to backfire.

Loss of Control

One point made clear by the Schulz and Hanusa research with nursing home residents is that it is more damaging psychologically to believe that one has some degree of control or behavioral freedom and then to lose it than it is to think that one has never had control in the first place. In fact, this is the central thesis of a chapter by Camille Wortman and Jack Brehm (1975) on the general topic of behavioral control. They argue that there is often a two-step response to a severe loss of an important behavioral freedom. As might be expected, the first reaction is characterized by increased attempts to restore the freedom; the second step, however, is the opposite. The individual begins to realize that he or she has lost freedom and that there is little or nothing to do about it. It is this second step that leads to feelings of resignation and learned helplessness.

This monograph is based on Brehm's earlier theory of psychological reactance (1966). The theory suggests that when a person perceives that he or she is losing the freedom to perform a particular behavior (e.g., deciding where one wants to work or live), that individual will react by trying to regain the freedom. At the same time, the attractiveness of the behavior increases sharply for the person. Brehm (Brehm, 1966; Brehm & Brehm, 1981) states that there are two prerequisites for reactance to occur: a) The behavior and the freedom to perform that behavior must be important to the individual; b) The individual must believe that he or she actually had the freedom to perform the behavior at one time. Psychological reactance is not likely to occur if the individual believes either that he or she was not free or able to perform the behavior in the first place, or if the individual was not aware that the freedom existed.

Unfortunately, Brehm's theory has never been

applied to situations in which an individual perceives that others possess freedoms that they themselves have been unable to develop. In particular, the question of the extent to which disabled people desire to assert behavioral freedoms that others have but that they do not have remains, for the most part, unanswered. The theory does suggest, however, that once the individual believes that a particular type of freedom is potentially available, any limits or restrictions placed on that potential lead to increased efforts to assert the freedom. In an independent living situation, it would be expected that once a disabled person becomes aware of the types of freedom that are associated with independent living, this awareness should increase the person's desire to achieve those freedoms. In short, the movement may act as its own impetus, necessarily attracting more and more consumers as its public visibility increases. Also, once the freedom of independence is recognized and experienced by persons with disabilities, they are likely to react very strongly against attempts to place restrictions on that freedom, including proposed cuts in funding and/or legislation that is thought to be restrictive.

Summary

Brehm's theory and the work of Wortman and Brehm are particularly appropriate to a discussion of independent living. Their research, together with that of Seligman and his colleagues, indicates that people have a need for behavioral freedom as well as control, and they will react against any attempts to restrict that freedom. Such a reaction is initially constructive and of benefit to the individual's psychological health. In contrast, the individual who perceives that there is nothing that can be done to reassert behavioral freedom may begin to feel a lack of control and enter a state of helplessness and hopelessness. This severe reaction is likely for people who believe that they once had, but have now lost, all control of behavioral freedoms.

One last point on this issue should be mentioned. Seligman has suggested that one way to counteract this depressed state is to strongly encourage individuals to attempt new behaviors that are guaranteed to be effective. This demonstrates to them that there is some-

thing they can do to help themselves. Once they realize this, they should be able to resume the learning process. Of course, there are some limits to this approach. It would be pointless to demand that an individual attempt new behaviors--one person cannot force motivation on another. Nonetheless, demonstrating that people are capable of performing many of the functions that are a part of independence--and that could require a considerable amount of encouragement--might be sufficient to convince them to try. For many people, the primary obstacle to complete independence may be the psychological barrier that comes with lack of familiarity or simply lack of awareness of what can be done. For various reasons, the freedoms of persons with disabilities may be restricted simply by the fact that they are unaware of how much independence is actually available to them. Once they become aware of what independence means, ideally from demonstrations by others with disabilities who are living independently, this barrier might be overcome. This careful demonstration is also likely to inhibit the attribution process that promotes helplessness (cf. Weisz, 1981).

Differences in the Desire for Independence

One aspect of independence seems to be universal. The need for control in one form or another appears to be basic to human nature. When it is lost, the individual often suffers definite, sometimes severe negative consequences psychologically. Because there are consistencies in responses to loss of control does not mean that the need itself is consistent from one person to the next. On the contrary, research suggests that there are large individual differences in both the need for freedom and control and in reactions to independence. These differences are a function of a number of characteristics of the individual, the most important of which are his or her previous experiences with independence and freedom. Persons with disabilities vary enormously. Some have experienced almost total freedom in the past, some hardly any. Some disabilities might severely limit some people's expression of independence, while other people have no obvious restrictions. In short, there is an incredible range in the independent living movement, and no one program or

policy will effectively serve the needs of everyone involved. To better understand this diversity of needs, it is necessary to examine the background of the consumer.

In a provocative work entitled Asylums, Goffman (1963) talks about the kind of environment that existed in institutions and many hospitals throughout the early 1960s. He uses the term total institution to refer to places where the individual surrenders virtually all sense of responsibility to the hospital and its staff members. As a result, residents become almost totally dependent on the institution for day-to-day functioning, sometimes to the point where they may refuse attempts to increase the control they have over their lives and even grow reluctant to leave the institution when it comes time to do so. Institutions have changed noticeably in the last 20 years, but this type of dependency problem is likely to remain prevalent as long as the emphasis on deinstitutionalization is maintained. Although it is difficult to understand why a person would actually reject independence when offered, some insight into this question is found (once again) in theoretical work by Brehm.

Brehm and his students have been actively engaged in research into his theory of motivational suppression (Brehm, 1982). The theory is similar to reactance and, in fact, has its roots in the cognitive consistency theory tradition (Brehm & Cohen, 1962).

They suggest that the amount of motivation or what Brehm calls energization an individual invests in attaining a particular goal, and also the actual attractiveness of that goal, are both functions of the person's perceptions of his or her ability to attain it. If someone believes that a goal is within his or her reach but realizes that achieving it will require considerable effort, chances are high that effort will be expended, and the goal will take on new and added value. However, an object or behavior that is thought to be easily reached is not seen as particularly attractive, and relatively little energy is put into achieving it. Similarly, a goal thought to be impossible to achieve is devalued, and the energy that might have been invested in reaching it is suppressed.

This concept is relevant to a discussion of re-

strictive environments and independence. For example, it suggests that an institutionalized person or a disabled person living at home who has spent many years in a highly dependent living situation might firmly believe that independence is beyond his or her reach. Indeed, as Goffman has suggested, independent behavior is often discouraged in these settings. Consequently, the person living in an institution or in any other dependent living situation may very well decide dependence is a way of life--the only life available. People who feel this way are likely to suppress any desire to achieve independence, thus substantially reducing the appeal of freedom. When it comes time to leave the institution or family, they are psychologically unprepared for the community and have convinced themselves that they do not want independence and are not prepared to invest any energy to achieve it.

An analogous situation is described in a paper by Averill (1973). He suggests that sometimes believing that one has control over one's environment might be stressful. The reason is that being able to control various factors that influence one's life places pressures on the individual to perform or perhaps overcome adversity. Fromm (1941) refers to this as the burden of freedom. That pressure can be very difficult to handle. First of all, there is the risk of failure and the damage that both worrying about the failure and the failure itself can cause. With freedom comes responsibility. The more control people have, the more responsibility they must accept for the consequences of their behavior. And even if the person is successful, it could appear that the reward does not outweigh the cost of the effort or the concern that possible failure has promoted. In general, the stress appears to be a function of how important the person thinks the control is and how extensive the consequences of failure are anticipated to be. Once again, the difficulty produced by this stress is likely to vary from one person to the next.

Without data, it is difficult to predict how individuals react to the stress that accompanies independence. An important factor is the person's previous history with independent or nonindependent living environments. Individuals who perceive that they once had control and have given it up will experience a strong need to reassert that freedom, presumably in a nonre-

strictive environment. On the other hand, persons who have lived most of their lives in a dependent living environment or an institution may have experienced independence only vicariously. They may not be fully aware of what independence really means and may not want freedom and the problems that come along with it--at least not right away. Even if such people are capable of living independently, they may feel that the stress associated with freedom outweighs the benefits. Regardless of their capabilities, if they have suppressed the desire to have control, they will not exert the effort required to have an independent existence. Under these circumstances, immediate independence could be more harmful than helpful.

In this situation, the first step toward resolution might be to convince clients that they are capable of accepting more responsibility by encouraging attempts at new behaviors in a transitional environment. Thus, a program of service delivery that effectively eases clients into supportive independent-type environments may be preferable, especially for persons who have been institutionalized for a long time, individuals who are mentally retarded, or those who have had no previous experience with behavioral and decisional freedom.

The Client in the Community

As the independent living movement gains momentum, the visibility of persons with physical and mental disabilities in community settings will increase as will the amount of contact they have with members of the community. How will community members respond to a growing group of disabled people who are living in the community? This continues to be a very important question from the perspective of policy planners, advocates, consumers, and social scientists. It is also a question that has received some (though not much) empirical attention in the last 7 or 8 years. Specifically, the question is this: What attitudes and behaviors can disabled people expect from others whom they meet in the community?

A significant proportion of research in this area has stemmed from theoretical work by Katz and Glass

(Katz, 1981; Katz & Glass, 1979). The basic contention of Katz and Glass's theory is that attitudes toward persons with disabilities are characterized by ambivalence. On the one hand, nondisabled people have feelings of sympathy and admiration for the courage and determination demonstrated by persons with disabilities. However, at the same time, they are also likely to have feelings of distaste and, perhaps, aversion. As might be expected, these ambivalent attitudes often translate into a confusing behavioral pattern. Sometimes nondisabled persons may respond more to the positive component of their feelings and sometimes more to the negative. Predicting which is likely to manifest itself is very difficult.

The object of one of our studies in this area (Gibbons, Stephan, Stephenson, & Petty, 1980) was to determine under what circumstances the sympathetic and aversive components of ambivalent attitudes are likely to predominate when a disabled person interacts with a nondisabled person. We had college students work on a task with teammates who were physically disabled and teammates who were nondisabled. The finding was that how the disabled person's behavior affected the nondisabled observer was a determining factor in the interaction. When team members failed on a task they and their nondisabled partners were working on together, they received much more blame (and were liked less) if they were disabled than if they were nondisabled. In other words, what we found was a classic example of scapegoating. Disabled persons took more than their share of the blame for problems nondisabled persons shared with them.

These results can be generalized to situations outside the laboratory. The study suggests that a person with a disability who displays incompetent behavior may receive more blame than a nondisabled person who has made the same mistake.

Consider, for example, the reaction that is likely to be elicited by a mentally retarded woman who is holding up the checkout line at a grocery store because she does not have the correct change, or (worse yet) has no money at all, or by a man in a wheelchair who drops his tray in the cafeteria line. These people are quite likely to be targets of more ridicule than are persons without disabilities who are having the same

problems.

The negative component of the ambivalent attitude is not likely to be manifested unless there is some ostensible reason to justify it. In fact, one of the more interesting suggestions to come out of our study and others (e.g., Snyder et al., 1979) is that discrimination against disabled persons in a real-world situation is likely to be very subtle. It is generally considered poor form, for example, to make some comment about an individual's prosthetic device or to complain when the person's wheelchair runs over one's toe. It would be much more likely, however, for prejudice to be demonstrated in a situation that was more ambiguous, where it was not completely clear that discriminatory attitudes or actions were being displayed. Thus, one might simply choose to avoid a restaurant consistently patronized by persons in wheelchairs (claiming, when asked, that one considers the food there not very good), or one might choose to vote against curb cuts and ramps because they are too expensive or because other (unspecified) social programs should have higher priority.

Positive Prejudice

There is another side to this problem. There are situations in which the disabled person is expected to receive the benefit of the doubt. In particular, the disabled person who is living in the community and obviously doing well (i.e., well-adjusted, competent, professionally successful, etc.) might receive more praise for accomplishments than an equally successful person who is not disabled. In attributional terms, this is referred to as an augmentation effect. This means that a person who can perform a task despite an obvious inhibiting factor has greater ability or (as is more likely with disabled persons) more motivation than someone who has done the same thing without a disability to overcome. In either case, the person is generally seen in a more favorable light and is liked more because of it.

Even though a reaction of positive prejudice can sometimes be beneficial to the disabled individual, the disadvantages associated with ambivalence in nondisabled persons outweigh the advantages. Not knowing how

others are likely to respond to one's behavior can be very stressful. Moreover, problems are exacerbated by the independent living movement simply because there are more opportunities for others to display their ambivalent feelings. Independence puts extra pressure on disabled people and affects both what is expected of them and what rewards they expect to receive. An independent person who appears to be coping adequately in the community is likely to receive the benefit of the doubt, the extra favor at the right time, or additional cooperation when it is needed. But the converse is true as well. A disabled person who is struggling in the community is likely to have it much tougher there than in a sheltered environment and certainly much tougher than a nondisabled person would under the same circumstances.

Preparing disabled persons for the environment they are likely to face in the community, in terms of the attitudes and behavior of people they meet and interact with, should be a high priority for ILCs. It is first necessary to find out what disabled people expect from community members, based on their previous experiences. These experiences can then be shared with other disabled individuals. In fact, the best preparation persons with disabilities receive will come from others like themselves, people who have had similar experiences. This is the basis for peer counseling programs used in ILCs.

Independence and Mentally Retarded People

Although mentally retarded people living in community settings have traditionally not been participants in the independent living movement, this situation will change as they become more aware of the services available to them and more vocal in their demands for those services. For a number of reasons (some of which are described below), independence has a different impact on this segment of the developmentally disabled population than it has had on persons with physical disabilities. People who are mentally retarded view independence differently. They have different needs for freedom and control. When they are in the community, they are likely to evoke different reactions from individuals who come in contact with them. They are unique people with unique problems. For this reason, I have chosen to deal with this group separately. In doing

so, I shall present some of the work pertinent to a discussion of independence, beginning with our own. Most of this research focuses on the social climate that is likely to develop in community settings that include people with mental disabilities.

Our earliest work (Gibbons, Sawin, & Gibbons, 1979) in this area concerned the perceptions of nonretarded people about the abilities of retarded individuals to function socially on a day-to-day basis in a community-like setting. In particular, we looked at the predictions college students made for the behavioral outcomes of mentally retarded people (e.g., success at work, popularity with friends, social skills, etc.). We presented the college students with descriptions of individuals who were retarded and nonretarded and were either socially active and successful (had plenty of friends, remained active, seemed happy, etc.) or inactive and less successful (few friends, difficulty at work, etc.). We then asked the college students to make predictions for future social behavior and to give explanations of causal attributions for previous social behaviors.

The college students had very low behavioral expectations for those who were mentally retarded. They expected them to fail at a number of noncognitive behaviors that should not be greatly influenced by level of intelligence. These included the ability to find employment, likelihood of getting married, ability to raise a family, etc. In general, the college students tended to make external attributions for outcomes of those who were retarded and indicated that these individuals had little or no control over their lives. Instead, they saw retarded persons as being at the mercy of exogenous factors (such as luck) and especially susceptible to other people's influence. In other words, they saw them as being highly dependent.

Consistent with this lack of control perception, college students also revealed evidence of patronization. They did not give retarded people as much credit for success as they did nonretarded people, nor did they blame them as much (or at all, in some cases) after identical failures. People who were retarded were not seen as being responsible for their own lives. The students apparently saw little point in blaming them if they could not bake a cake or make friends or

hold down a job. By the same token, mentally retarded individuals who could do these things and do them well were thought to be flukes whose success was a chance or lucky event not likely to recur. Another study (Gibbons, Gibbons, & Kassin, 1981) indicated that the patronization pattern may carry over into the courtroom. In this study, hypothetical criminal offenders received less blame and lighter sentences, regardless of the crime committed, when they were said to be mentally retarded. Again, the reasoning appeared to be that retarded people are not completely responsible for or in control of their own behavior.

This research suggests that, at the very least, nonretarded people are skeptical about the abilities of retarded people to function in a nonsupervised environment. Although this does not necessarily mean that people in the community favor institutional placements for those who are disabled, it does suggest that support for more independent living arrangements in community settings may sometimes be less than wholehearted. Many people need to be convinced that independence is a viable concept before they will offer their support. They must be convinced that disabled people can function independently. If nondisabled individuals expect independent living centers to fail, there are many circumstances they can condone to make those expectations come true. Even skepticism from certain individuals in the community at certain times can cause problems for a disabled person looking for employment or access to a particular political committee or advisory board.

Research in community attitudes toward mentally retarded people living in the community has not been favorable or encouraging (e.g., Gottlieb & Corman, 1975). Most of the research was conducted before the independent living, or, for that matter, even deinstitutionalization movements had reached their peaks. Consequently, the full impact of these programs, in terms of their effect on societal attitudes, has not been accurately reflected. The process is definitely a two-way street. Just as the attitudes of community members have a significant effect on what happens to ILCs, ILCs have an effect on the attitudes of people in the community. More research is needed to determine what effect ILCs are having on the many individuals who are directly and indirectly involved in the independent

living movement.

The Center and Its Consumers

The attitudes that ILC consumers are likely to face in the community have a profound influence on the centers themselves, including how quickly they become established and how smoothly they function. Whether centers survive or fail, however, is determined ultimately by what happens inside the centers--in other words, how consumers relate to each other. Although a reasonable amount of research has examined how nondisabled persons view those who are disabled, the question of how disabled people view each other has been virtually ignored.

By its very nature, independent living promotes interactions among disabled persons and encourages them to rely heavily on each other (as well as on themselves), not only for assistance in day-to-day functioning, but also (and perhaps more important) for the encouragement and support that is essential to independence. Evidence of this is the extent to which ILCs are staffed by people with disabilities. The issue of living and working together raises a number of questions. For example, the general question of how disabled people view and relate to each other and to themselves is basic. Questions of equal importance, such as the following, also need to be asked: Do disabled people prefer the company of others similar to themselves, or does the company of other disabled individuals serve as a reminder of their own disability? Do they prefer to date other individuals with disabilities? Do they see disabled people as less physically attractive than nondisabled people? What kinds of behavioral expectations do they have for others like themselves? The attitudes revealed by these questions can make the difference between a successful program and one that in the long run could foster less, rather than more, independence among its consumers.

Social Relations Among Mentally Retarded People

The most truly independent living arrangements are

those that promote interdependence in relationships among inhabitants. One factor that influences how persons with disabilities relate to each other is their perception of the stigma associated with disabilities. We have looked at this question (cf. Gibbons, 1981) and examined how awareness of the stigma affects social relationships among disabled people, primarily people with mental retardation. This first step was to look at awareness of what the label mentally retarded denoted and connoted. We had evidence of patronization in our previous work with nonretarded individuals and decided to examine this phenomenon among our sample of mentally retarded people.

Earlier studies (Gibbons & Gibbons, 1980; Gibbons & Kassin, 1982) suggested that people with mental retardation living in state institutions were very much aware of the negative connotations of the labels institutionalized and mentally retarded. Moreover, this awareness seemed to carry with it some prejudice. Institutionalized people typically reported that they would prefer not to have other institutionalized retarded people as friends, roommates, and workmates, if they had a choice. They also reported that mentally retarded people were less intelligent than nonretarded persons, less likely to perform adequately on cognitive tasks (such as jigsaw puzzles), and, most important, less likely to have what would be considered a normal social life, including getting married and raising a family. The prejudice these people were demonstrating was directed as much to the institution itself as to those in it. Apparently, they had learned--from a variety of sources--what the term institutionalized, mentally retarded meant to the community outside the institution--and that the institution was a place for individuals who were incompetent or (more accurately) socially inept.

We also asked retarded people for their self-expectations in terms of specific abilities to perform a cognitive task, as well as their general expectations for future social behavior. Their responses to these questions indicated that they had higher expectations for themselves on the cognitive tasks than they did for their retarded peers. Their self-expectations fell between their predictions for retarded and nonretarded persons. Thus, they perceived themselves as being more competent cognitively than the average mentally retard-

ed person. In contrast, their expectations for their own social behavior were very low--as low as those that they maintained for the retarded people (and lower than those for nonretarded people). One reason may be the relatively poor opinions they hold of other retarded people's social skills (see below). If they see other retarded people--who are likely to be the targets of most of their social interactions--as socially unskilled, then it stands to reason that they would have relatively pessimistic predictions of their own chances for social success. In this sense, the stigma perception can act as a self-fulfilling prophecy. As long as mentally retarded people hold negative impressions of each other, their social interactions and self-perceptions are likely to be hampered. Moreover, their social lives (and lives in general) are likely to be restricted.

One particular finding that stood out in that early research was that the low opinions of retarded peers were particularly evident in the cross-sex evaluations, with mentally retarded females being harshest on mentally retarded males (more so than on nonretarded males). Our current research is looking at cross-sex perceptions and relationships among mentally retarded persons to see how they are related to social behavior. This time, we will be comparing the responses of institutionalized people with those of people living in more independent community environments to see if there are differences in the social behavior patterns within the two types of residences and to see if differences are related to satisfaction with social lives. In particular, we are obtaining a rough measure of the amount of social freedom available in community facilities to determine whether this factor is related to levels of adjustment to living environments.

Only recently has much attention been given to social skills and satisfaction with social lives as part of successful community adjustment. Unfortunately, some studies report that many mentally retarded people have trouble adjusting in these settings. Birenbaum and Re (1979), for example, conducted a 4-year follow-up study of clients of a community facility and found that the clients' lives became more routinized, and they appeared to be less independent after 4 years. Nonetheless, most clients preferred a more independent environment. The leading choice of living arrangements

was a separate apartment.

In addition, this research revealed two social factors that, suprisingly, seemed to be strongly related to social adjustment. Landesmann-Dwyer, Berkshon, and Romer (1979) found that mentally retarded people who maintained active contact with their parents while living in a group home appeared to be more socially isolated from their peers than others who were more independent of their parents. By the same token, some independence from peers also seemed to be beneficial. Reiter and Levi (1981) found that having nonretarded friends was very important to the well-being of community-based subjects who were mentally retarded. Those whose peer group consisted exclusively of other mentally retarded people were not doing as well as those with a mixture of mentally retarded and non-retarded friends.

Our own research suggests that the negative opinions that some institutionalized retarded individuals have of mentally retarded people of the opposite sex might be at the core of this apparent social or group concept problem. This (social) aspect of behavior should be a primary concern of those in the institution who are preparing mentally retarded people for life in the community. Specifically, this would include allowing and (where necessary) actively promoting social interactions between male and female residents, tolerating personal relationships and, perhaps most important, providing sexual and social education for mentally retarded adolescents and young adults. The issue of social freedom within the institution is clearly a difficult one. If it is assumed that one of the institution's primary goals is to prepare residents for less restrictive environments, every effort should be made to normalize the social environments that exist in institutions. In other words, the more social experiences people have inside the institutions, under settings that are more or less supervised, the more capable they become of handling social pressures in the community.

Before leaving this topic, I should point out that all research in this area is not pessimistic. A series of studies by Romer and Berkshon (1980; Berkshon & Romer, 1980) shows a more positive social interaction among mentally retarded people. They have demonstrat-

ed, for example, that mentally retarded people in independent environments, such as sheltered workshops, spend considerably more time socializing with each other than with staff members. In addition, like non-retarded persons, they tend to seek out other mentally retarded people who are similar to themselves (e.g., in terms of physical attractiveness) as friends. Many of the principles that apply to social relationships among nonretarded people could be applicable to mentally retarded populations in noninstitutional settings. Right now, the data on cross-sex relationships are sketchy. The more data we collect, however, the more important this variable appears to be.

There are two additional questions raised by this research on stigma perceptions among those who are disabled, the answers to which may help those involved in organizing ILCs determine where priorities should be placed. The first question is how do individuals with physical disabilities perceive other disabled individuals? In particular, do they maintain ambivalent attitudes toward each other? Are they oversolicitous of successful peers, thereby undermining intrinsic motivation? Are they overharsh on less competent colleagues, thereby inhibiting the latter from asserting themselves? Just as the notion of group concept might be a problem for mentally retarded individuals living independently, ambivalence might be a problem for disabled people trying to establish an effective interdependent living arrangement.

The second question is how people with different types of disabilities perceive and relate to each other. Changes in federal laws over the past decade have resulted in the term handicapped being expanded to include more and more people with different disabilities, all of whom are interested in obtaining funding for essential services. The Reagan administration's move toward state autonomy and state control of social funding has caused groups of disabled individuals to compete for very limited resources. The result of this unhealthy competition can exacerbate cross-stigma prejudice. This, in turn, can interfere with the independence and advocacy movements. Moreover, differences in the abilities of various consumer groups to advocate for their own causes inevitably results in some groups receiving a smaller share of the funding pie. Because mentally retarded people are the least capable at self-

advocacy, they are most likely to be hurt by this competition. In the long run, all consumer groups will be hurt if they are unable or unwilling to support each other in their efforts toward common goals. If this problem does exist--and that is yet to be determined--than the extent to which the problem is interfering with the movement and affecting the behavior of those who are part of it should be assessed.

Future Research

Research in this area suggests a very important empirical question. That is, what effect does the patronization response pattern have on mentally retarded people--specifically, on their motivation to succeed at what they are doing and to function successfully on their own? The clear message in the responses of college students to the mentally retarded people in our research was, "Why try when there is little you can do to help yourself?" To the extent that mentally retarded people accept this message, we can expect their motivation to be low. Likewise, should they carry this attitude into the community, their chances of attaining and maintaining independence are reduced. Our future work, then, will look at the extent to which mentally retarded people patronize themselves and each other, how this attitude affects specific behaviors such as achievement motivation, task persistence, and self-help abilities, and how it affects the social climate that develops in the community.

Finally, there is one point, although anecdotal, that is more optimistic and perhaps as revealing as the data presented. Our first pilot study was conducted with formerly institutionalized mentally retarded people (protegees) from a citizen advocacy program in Texas. At the end of our interviews, we asked them whether they would like to go back into the institution. As one might expect, with no exceptions the answer was "no." More important, when we asked them why they would like to continue living outside the institution, the clear consensus was that they liked the freedom to come and go and do as they pleased. In spite of all the difficulties, they did not want to give that up.

Is Independence Worth the Risk?

Two major points in the IL movement can be concluded from the research presented here. The first is that there is every reason to believe that individuals with disabilities, including those who are mentally retarded, like the freedom associated with independence. The second is that independence brings serious problems that place a considerable amount of added pressure on persons with disabilities. One such problem is that independent living (and the philosophy associated with it) requires much more intense interactions among disabled people. This may serve to exacerbate the psychological problems associated with their various stigmas. This may be one reason why some research has indicated that the level of social adjustment of people who are mentally retarded in the community does not always improve with time.

Another problem is that having control over one's life (including behavioral freedom) can in itself be stressful, especially for people who have not had freedom in the past. Independence requires more initiative and effort and could lead to more failures and the potentially debilitating causal attributions associated with failure. In this regard, recent work in the area of attribution theory has indicated that individuals avoid information that might show that their failures are due to low ability and that they prefer to avoid situations that might provide this information. Thus, it could very well be that a disabled person might not be willing to find out if he or she can live independently, because he or she may not consider the rewards sufficient to outweigh the risk of failure.

These are definitely real and serious issues. There is no doubt that with independence come difficult problems, many of which would not exist for persons living in more dependent environments. In fact, given the amount of time I have spent describing and discussing these problems, the reader may have the impression that the research--or at least my interpretation of it--suggests that independence is just not worth the risk.

In a provocative and informative paper, Robert

Perske (1972) talks about the risks involved in living in nondependent environments. With the help of a Dybwad award, Perske observed the service delivery systems for mentally retarded people in Scandinavia. He noted that in those countries, much more so than here, mentally retarded people are encouraged to go out into the community, try new behaviors, and attempt to live normal lives. Independence is almost forced upon them. Of course, they run a great risk of failing, and they do fail quite often. But Perske (like many service providers in Scandinavia) does not see this as a bad thing. In fact, he has quite the opposite opinion. He believes that something can be learned from trying and failing and to deny disabled persons the opportunity to try normal behaviors, even though they are bound to fail, is to deny them basic human dignity. There is, he says, a dignity of risk that all humans, whether disabled or not, should have the opportunity to experience.

Determining ahead of time how much risk is appropriate and how much failure can be tolerated would be very difficult for any person. That can only be learned from experience. It is also likely to vary considerably from one person to the next. Total independence is certainly not for everyone. The point is that we have little choice--many disabled people believe there simply is no acceptable alternative. We do know what the consequences of dependency and the loss of freedom associated with it are, and those consequences are not tolerable. The laws and the mandates are very clear--whatever needs to be done to promote normalization among disabled persons and to provide them with an environment that is least restrictive will be done. By any definition, that environment includes independence. In sum, independence is vital, it is necessary, and it is essential to mental health. But it does not come easily.

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COMMENTARY

by John H. Berg

I was immediately interested when I was asked to write a commentary on Gibbons' monograph, "A Social Psychological Perspective," because I am both a social psychologist and a disabled person living independently. In reading the monograph, I was repeatedly reminded of the often-used (and perhaps overused) remark of Kurt Lewin concerning how practical good theories are. The study of independent living epitomizes the Lewinian concept of action research. In this approach, data from the experimental laboratory are integrated with data from the field, and the result is applied to the solution of social problems. While almost every social psychologist pays lip service to this ideal, it is all too seldom practiced. Gibbons makes it clear that there is much social psychology can contribute to the independent living movement. There is also much it can gain. I believe both the movement and social psychology will be the poorer, if social psychologists fail to address the really important issues where there are common gains to be made.

One process social psychologists have begun to explore (which has broad implications for independent living) is the process of social interaction. Social interaction, however, involves numerous subprocesses, each of which impacts on the disabled person attempting to live independently. One subprocess social psychologists have given considerable research attention to is social perception. While examples of social perception can be found throughout the monograph, they are perhaps most apparent in the section called, "The Client in the Community." Two sets of perceptions are involved here: those of the disabled person and those of the nondisabled person.

About the former, we currently know very little. One recent study (Kleck & Strenta, 1980) suggests that people who believe themselves to be physically stigmatized tend to interpret the responses of others as reactions to that stigma, regardless of what those responses might actually be. If this is correct, or if a disabled person is aware of the potential operation of positive prejudice, he or she could very well discount expressions of support or praise. The disabled individual might, in effect, say, "Oh, she doesn't really believe I have much ability. She feels sorry for me and is just trying to be nice and make me feel good." I do not know when a process such as this would

be most likely, but should it exist, it would have a profound impact on the adjustment and self-concept of the disabled person.

A second set of questions involving the perceptions of disabled people concerns the manner in which they perceive themselves and their alternatives. The latter aspect of this question is addressed in the sections dealing with control. As Gibbons notes, the degree to which people believe they have control over significant life events or outcomes is of tremendous importance for their motivation to become more independent. Gibbons also notes that a lack of awareness of what can be accomplished may be the greatest obstacle for many individuals. In this regard, it can be of great help if there is contact between people who are living more independently and their less independent colleagues. Encouragement to become independent could be more effective with exposure to others with similar handicaps who are independent. I wish to note here the contribution made by many returning Viet Nam veterans. These men wanted, expected, and demanded more control over their lives and thus served as models for other disabled people. The task of increasing awareness is, however, far from complete. The comment of a disabled man in a support group in which I was participating comes to mind here. He said, in effect, that he expected very little and had learned to "be grateful for crumbs." Regardless of whether this was true, the fact that such a statement would be made is indicative of the helplessness or hopelessness that can occur when people view themselves as having no alternatives.

While the existence of models may increase the awareness disabled people have of the amount of control they can exert, Gibbons also adds a caution. The work of Schultz & Hanusa that he reviews makes it appear crucial that perceptions of control be vertical. If early attempts at control meet with failure, it is unlikely that motivation will continue. This is not to say a disabled person can or should be protected from all failures. To do so is impossible and, perhaps more important, denies the individual dignity. Goals, however, should be realistic, and attempts should be made to prepare the person for the difficulties she or he may encounter and to learn from failures to achieve these goals. Here again, contact with other disabled individuals who are living independently is useful.

The question of how disabled persons perceive themselves is not addressed to any large extent by Gibbons, but it is also an area in which social psychology can make a significant contribution. The work of Duval and Wicklund (1972) suggests that when individuals focus on themselves, they become aware of discrepancies between the way they are and the way they would like to be. If there are no means by which they can reduce these discrepancies, they will attempt to avoid the situation that led them to focus on themselves. Duval and Wicklund note that a potent stimulus leading to such self-attention is the perception that others are watching you and what you are doing. The disabled person who feels that she or he stands out and is the object of a crowd's attention may thus become anxious and avoid social situations. The temptation to view oneself as the object of everyone else's attention may be exacerbated when extraordinary measures must be taken to permit a disabled person's access. As accessibility for disabled people becomes more routine, the avoidance process should decline. Feeling oneself to be the focus of others' attention might also decline with experience and with routine accessibility. The tendency of nondisabled persons to stare at a novel event should decline as well.

An additional factor likely to affect the way in which disabled persons view themselves and their alternatives is the amount of time they have lived with their disability. Someone who becomes disabled later in life may be particularly likely to feel a loss of control. Research attention also needs to be paid to the manner in which individuals with different disabilities differ. In this regard, the monograph is perhaps too inclusive. Speaking of an undifferentiated independent living movement obscures important differences among individuals with different disabilities. We do not know to what extent people with particular disabilities perceive themselves and the problems they encounter as being similar or dissimilar to problems faced by people with other disabilities.

The second set of perceptions I want to discuss briefly are those of the nondisabled individual. As Gibbons notes, most of what is known about reactions to disabled people comes from the work of Katz and Glass. In the section on "The Client in the Community," Gib-

bons discusses the ambiguous attitude many people have toward disabled people. While some may feel sympathy and admiration for a disabled person, there can also be a similar amount of distaste and aversion. For many individuals, contact with a person who is disabled might threaten a belief in a just world where we get what we deserve and deserve what we get. It is the threat to this belief that could underlie feelings of distaste and aversion.

Furthermore, the feelings of sympathy and admiration that contribute to the operation of positive prejudice can also have negative implications for disabled persons attempting to live independently. As noted above, awareness of positive prejudice might lead a disabled person to discount the praise of others. Even if such praise is not discounted, it could place an added responsibility on the disabled person living independently. Lavish praise, especially when given for what one views as a routine task, could create an added burden of living up to such praise. I have met several disabled people who have been quite successful at living independently but who react very strongly when others tell them how much they are admired.

One final question is social perception, about which we know little, but to which social psychologists may provide answers concerning the manner in which both disabled and nondisabled people organize information about individuals with disabilities. A study by Brewer, Dull, and Lui (1981) indicates that information about the elderly is hierarchically organized into types and prototypes. This study could serve as an example for similar investigations into the ways disabled people are perceived. The questions one might explore would include the following: How do disabled and nondisabled people differ in the way in which they perceive and organize information about individuals with disabilities? Is this information processed or organized differently for different disabilities? What behaviors are seen as most associated with different disabilities?

A final comment concerns the question Gibbons raises in the concluding section of his paper about whether independent living is worth the added risks, responsibilities, and problems it entails. I do not presume to answer for all people with disabilities and

would respect whatever decisions others might make.
However, as a disabled person living independently, my
answer to this question is a most emphatic "Yes!"

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