

A PHILOSOPHICAL FOUNDATION FOR THE INDEPENDENT LIVING  
& DISABILITY RIGHTS MOVEMENTS

by

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## FORWARD

We at ILRU are pleased to publish this philosophical perspective of independent living. This paper represents an extensive amount of personal reflection and study on the nature of independent living extending back over the past two decades. Embodied within the paper are a blend of philosophical concepts from many cultures and critical lessons from personal experiences. The theme of independent living begins to assume a universal identity through this discourse, and many readers will no doubt recognize the value of this approach to the movement.

The authors are well qualified to address the issues which they raise in this paper. Each of them has been involved in independent living program development and operation, each has made numerous site visits to programs all over the United States, and each has been intimately involved in the disability rights movement. In addition, much of the content of this paper was influenced by discussions with leaders of the independent living movement and by a recent series of visits to more than twenty independent living programs across the country.

Some of the subtle philosophical issues raised in this paper by their nature do not lend themselves to discussions in simple and concise terms. And, it is expected that some readers will question the application of the principles which are set forth in the paper. Nevertheless, the ideas expressed throughout the paper, and the system of values which they represent, set a stage for forthright and earnest discussion which may lead to construction of a solid philosophical basis for the independent living movement. Furthermore, the future of the movement depends on a sound foundation, and this paper represents a vital, first effort to construct such a foundation.

Lex Frieden, Director

Laurel Richards, Materials Development  
Coordinator

Houston, 1982

We believe that handicappers are discriminated against by the rest of society on the basis of an erroneous and destructive stereotype. We believe that discrimination against handicappers must end. Most importantly, we believe that handicappers can and should take the lead in ending that discrimination.

"Philosophy Statement" of the  
Center of Handicapper Affairs  
Lansing, Michigan

We are in the business of changing the world.

Beverly Chapman, Executive Director  
Center for Independent Living in  
Central Florida

. . . man being condemned to be free carries the weight of the whole world on his shoulders; he is responsible for the world and for himself as a way of being. . . . the peculiar character of human morality is that it is without excuse.

Jean Paul Sartre

Does not the essence of man, does not his belonging to Being, does not the essence of Being itself remain ever yet and ever more overwhelmingly what befits thought? . . . That is the question. That is the world question of thought. Its answer will decide what becomes of the earth and of the existence of man on this earth.

Martin Heidegger

The paramount goal of the United States was set long ago. It is to guard the rights of the individual, to ensure his development, and to enlarge his opportunity. . . . Our enduring aim is to build a nation and help build a world in which every human being shall be free to develop his capacities to the fullest. We must rededicate ourselves to this principle and thereby strengthen its appeal to a world in political, social, economic, and technological revolution.

Wrist on, Pace, Canham, Conant,  
Darden, Greenwalt, Gruenther,  
Hand, Kerr, Killian, and Meany  
(The Commission on Goals for  
Americans appointed by President  
Eisenhower)

## Introduction

During the spring and summer of 1980 we undertook to become familiar with the situations of the leading American independent living programs and to obtain the advice of individuals who have been successful in independent living philosophy, management and research. Two members of our team made three national trips, visiting more than 30 organizations, and contacted a good number of other programs and resource persons by telephone and mail. That study, and our combined 34 years experience in the independent living and disability rights movement, form the basis for the present work, and for another to follow (which will deal with the management of independent living programs).

Although we originally intended that our research result in a brief report on the organization and management of certain leading ILPs, the information we gathered seemed to suggest the need for a more comprehensive approach.

We perceived an infant movement attempting to achieve strongly felt but vaguely defined goals in a highly volatile socioeconomic atmosphere. We perceived dynamic individuals of history making natural abilities struggling to overcome the handicaps imposed on them by an obsolete value system and hundreds of generations of dependent, subservient roles--struggling to gain the understandings and the skills necessary to control, develop and communicate the message of a rapidly growing phenomenon of culture shaking potential. We perceived a need for long-range planning based on a careful analysis of the past and present, for a mastery of the arts of organization, politics, public relations and unity, and above all, for the laying of a refined, practical philosophical foundation.

Where are we going? How are we going to get there? Hopefully, by about 1985, the movement will begin to gain strength and momentum from the answers to these questions.

Frank Bowe

In this essay we will attempt to offer brief focuses on some of the basic problems and goals of that complex, discordant unity of passion for human dignity which is formed by the various individuals and organizations of the independent living and disability rights movement--and to suggest concept and activity directions for the 1980s and 90s. We do not believe that we are in serious disagreement on fundamental issues of principle with any major segment of our movement, but we do feel very strongly that success in the present, rapidly evolving psychosocial reality will require certain modifications of policy based on clarified focuses.

We recognize that almost all people either have or will at some time during their lives have significant physical, mental, economic, social, cultural, and/or educational disabilities and that the problems of and solutions for most of those disabilities are of the same fundamental nature. Therefore, it is extremely difficult, perhaps impossible, to construct a scientifically and philosophically profound definition which would enable accurate classification of every human as being either "disabled" or "non-disabled" in the conventional sense. Nevertheless there are, in the context of our current culture and language, large numbers of persons who have particular types of problems which are commonly called "disabilities," and who are the subjects of a great deal of focus and activity by individuals, organizations, governments and the communication media. In this writing we will, in most instances, use terms such as disability, disabled and handicapped, in more or less the conventional manner.

We have mentioned "the independent living and disability rights movement" and have implied inclusion of independent living programs in the reference. While each of these areas of activity does have certain distinctive



While disabled persons have been excluded from full participation in the American economic political system, they still subscribe to the system's most cherished values and assumptions.

Gerben DeJong

. . . for the first time in history, man has the real power to overcome poverty. We have proved that by the wise application of modern technology, the determined labor of skilled men and women can ultimately produce enough food and clothing and shelter for all mankind. The possession of new abilities gives us new responsibilities and we want to live up to those responsibilities.

Lyndon B. Johnson

characteristics, it is also true that they have much in common: substantially shared leadership, concepts, and emotions; almost identical long-range goals; and very similar problems and philosophical requirements. In the course of this writing we sometimes use the term "movement" to refer to all three phenomena.

It will be noted that we make references to the "establishment," and that we advocate some very fundamental social change. We are not, however, anti-establishment, nor do we intend to be any more critical of the establishment than we are of society as a whole, including ourselves. As a matter of fact the establishment has been responsible for most of the progress which formed the foundations of our movement. Specifically it has saved the lives of two of us, and made very substantial contributions to our rehabilitation. Neither do we condemn the current American, the modern technological society as being inferior to other societies of the present or past. On the contrary, it is demonstrably a society of unprecedented creative and productive power. It has produced strong evidence that many positive aspects of a standard of living previously associated principally with monarchs, myths and life after death are viable on a society-wide basis.

What we are saying here is that modern technological society has created its own special needs and its own magnificent potential--and therefore corresponding responsibilities. We are saying that we who are the society are failing in those responsibilities, failing to meet certain of those needs and to fulfill that potential, and that this situation, if allowed to continue, will seriously diminish the quality of, perhaps even destroy, our culture. We are saying that it is time for us to take the next steps--and that establishments do, probably in many instances as a legitimate expression of their nature and purpose, tend to resist certain types of change. The same

Clearly, alternatives are needed: Alternatives that restore dignity, responsibility, and power to the people on the bottom; alternatives that allow and encourage the poor to analyse the whole physical, social, and political reality of their situation and to organize so that they gain, through their own actions, greater control over their health and their lives.

David Werner

We shall here define progress as the increasing control of the environment by life . . . Consider education not as the painful accumulation of facts and dates and reigns, nor merely the necessary preparation of the individual to earn his keep in the world, but as the transmission of our mental, moral, technical and aesthetic heritage as fully as possible, for the enlargement of man's understanding, control, embellishment and enjoyment of life.

Will and Ariel Durant

responsibility to seek and expand quality of life (that responsibility which is fundamental to all human existence) which was the basis for the development of the present social patterns and establishment policies, now demands that we once again probe a wilderness of dazzling promise. We attempt to follow in the footsteps of our pioneering forefathers, to support our nation, our culture, our world in the most profound manner possible, by converting its highest ideals into living realities. That we insist to do this should be a matter of pride to the members of the establishment. It is a profound tribute to any parent generation that its offspring become dedicated to the fulfillment of its best goals. And we feel that a rational, modern society, sophisticated in the scientific method, will understand that there is much to be gained by--and no inherent contradiction involved in--the simultaneous sponsorship of established, traditional systems, and experimentation with promising non-traditional concepts.

We use the phrases "quality of life" and "life quality" in a special sense, which is discussed at some length in the text. Essentially we refer to those values which are inherent in the basic nature of human being and its inter-dependent society--values which are common to every culture and agreed upon by all persons regarded as sane. These are the values of survival, of life and its perceived quality--food, shelter, health, dignity, liberty, esthetic enjoyment and so forth. We have gathered these self-evident value-goal truths into a unity under the term: life quality.

We also employ an expanded definition of productivity. We believe that production can be meaningfully measured only in terms of the extent to which its results impact the total balance of life quality in the continuum which is self and society.

A nation's basic value system, shaped by history, tradition, and development, will be the primary influence on its approach to disability issues.

Monroe Berkowitz

We use the term "psychosocial" and the phrase "psychosocial patterns" to help communicate the poorly understood fact that the basic material of human being and human society is composed not of a series of relatively distinct phenomenal areas such as psychology, ideology, individual, society, and practice, but rather of a continuum of perceptual-activity patterns which radiate from and to (or within) the total universe formed by each personal consciousness--that psychology, concept, individual, society, and action are simply hypothetical focuses on undivided areas of one continuous system.

We urge caution in the interpretation of specific statements in this writing. Many of the definitions we propose, for example of life quality, the continuum which is I, society, and universe, and productivity, may seem rational, even fashionable. However in everyday discourse these terms and concepts are rarely used to express the precise meanings which we intend and which are essential to a correct understanding of our theses.

In an effort to communicate our material more effectively, we have utilized a counterpoint structure, with text on the right-hand page and complementary material on the left. We hope that this will help to overcome our literary limitations, and the difficulties involved in presenting a multidimensional universal continuum on a flat page, and in using a language and a style designed to convey the fragmented traditional concepts which we wish to modify.

We have not been able to completely resolve the problem of the gendered pronoun and other sex-based phraseology. Therefore we have, in some instances, settled for the usage of the generic "he" and similar terms.

We are indebted to a large number of our colleagues in the movement who, through their advice, writings and/or other activities, have contributed to

We are in the midst of a new philosophical revolution, a revolution in which, indeed, the new physics too has had due influence, but a revolution founded squarely on the disciplines concerned with life; biology, psychology, sociology, history, even theology and art criticism. . . The revolution before us is a revolution of life against dead nature, and of understanding against the calculi of logical machines.

Marjorie Grene

We are indeed on the edge of a great period of revolution. But it would be a great pity if our zeal were too easily assuaged by partial victories. We do well to recall that most revolutions have been lost precisely because they did not go far enough.

Jerome Bruner

the development of this essay. Space and memory do not permit listing them all--and by mentioning the following persons we do not mean to imply that they necessarily agree with all or any of our statements. Among those who generously gave their time and experience are: Monroe Berkowitz, Frank Bowe, Beverly Chapman, Bob Cooper, Bruce Curtis, Gerben DeJong, Dennis Dildy, Mary Lynn Fletcher, Lex Frieden, Laurie Gerken, Judy Heumann, Larry Johnson, IDAR Cody, Gini Laurie, Tom Morrison, Cole Murphy, John Nelson, Albert Pimentel, Bernard Posner, Pat Pound, Laurel Richards, Virginia Roberts, Len Sawisch, and Joe Veisz. Special thanks go to Jim Cannon and the members of MIGHT! (the disability rights advocacy organization in Austin, Texas), who sponsored the research project.

We earnestly solicit your corrections, criticisms and comments.

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The efficacy of the independent living concept is being proven each day by more and more severely disabled individuals as they choose to assume the responsibilities of directing their own lives and as they become active participants in the mainstream of life in their communities.

Lex Frieden

## A Philosophical Foundation

for the

### Independent Living and Disability Rights Movement

The disability rights movement has--through creative activism and the personal examples of its many outstanding members--recorded several decades of historic progress. One of its most promising accomplishments has been the establishment, during the past 10 years, of independent living programs, community based organizations providing advocacy and services designed to facilitate the efforts of individuals with disabilities to achieve an equitable social participation and quality of life. These dynamic experiments in human development, and the movement which sponsors them, offer the potential for substantial solutions not only for some of the major problems of the world's most severely disadvantaged minority--its 450 million disabled citizens--but also for the basically similar problems which prevent efficient utilization of humanity's vast personal, material and technological resources to produce maximal quality of life for all people. However the fulfillment of this awesome potential will, in the view of the authors, require significant modifications of concept and action. This writing will focus on selected problems and their solutions, and will outline what could be the beginning of a clarified philosophical foundation for the independent living and disability rights movement as a whole.

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Important questions have been asked such as: "What's new about the independent living (and disability rights) movement?" and "What distinguishes it from traditional rehabilitation that could justify claims of new concepts and approaches, calls for new organizations with disabled leadership, and allocations of scarce resources?" In order to achieve the necessary public

THE TASK

Every individual is entitled to full self-development and the chance to offer their unique abilities to the community in which they live.

Center for Independent Living  
in Central Florida

Independent living is not merely a collection of services, but an expression of our will to be independent.

Ingo Antonitsch  
Executive Director  
Denver Commission of  
the Disabled

support, in the context of the present culture, an organization must conform to certain established forms and definitions. But it is terribly misleading to attempt to distinguish the independent living movement only on the basis of these criteria: lists of services offered, types of clients served, percentages of disabled personnel on staff, and so forth.

There is something new and different about independent living; there is something that distinguishes authentic disability rights advocacy and independent living programs. Gerben DeJong has discussed the movement clearly and in some detail, in terms of civil rights, consumerism, and self-help; the rejection of traditional rehabilitation models and of the medical, sick, and impaired roles; deinstitutionalization, mainstreaming and normalization.<sup>1</sup> The ILRU Source Book has defined independent living as:

Control over one's life based on the choice of acceptable options . . . managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence upon others,

and goes on to point out that:

Independent living is not dependent upon programs that foster functional independence. Instead, it is based upon the individual's ability to choose and achieve a desired lifestyle and to function freely in society.<sup>2</sup>

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<sup>1</sup>Gerben DeJong, The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research (East Lansing: The University Centers for International Rehabilitation, Michigan State University, March 1, 1979).

<sup>2</sup>Lex Frieden, Laurel Richards, Jean Cole and David Baily, ILRU Source Book, A Technical Assistance Manual on Independent Living (Houston, The Institute for Rehabilitation & Research, 1979), p.3.

I have often inquired of myself, what great principle or idea it was that kept this Confederacy so long together. It was not the mere matter of the separation of the colonies from the motherland; but something in that Declaration giving liberty, not alone to the people of this country, but hope to the world for all future time. It was that which gave promise that in due time the weights should be lifted from the shoulders of all men, and that all should have an equal chance. This is the sentiment embodied in that Declaration of Independence . . .

Abraham Lincoln

I strongly believe that handicapped and disabled citizens must be given the opportunity to become self-reliant and independent.

William P. Clements, Jr.

The "Philosophy Statement" of the Center of Handicapper Affairs<sup>3</sup> declares:

We believe that handicappers are discriminated against by the rest of society on the basis of an erroneous and destructive stereotype. We believe that discrimination against handicappers must end. Most importantly, we believe that handicappers can and should take the lead in ending that discrimination. At the Center of Handicapper Affairs, we are dedicated to the initiation and implementation of programs designed to eliminate discrimination, equalize opportunities, and positive the image and self-concept of handicapper citizens.

Judy Heumann states, "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a 'normal' body."<sup>4</sup>

Bruce Curtis, in conversation, sums it all up in two words: "good politics." Although many among us would debate with him over details, and not all would be able to offer articulate definitions, there is no real doubt about what he means, or that his phrase reflects concepts, feelings, actions and commitments that define the movement at its best and that distinguish individuals or organizations as being authentic participants in the independent living process.

GOOD POLITICS ATTACKS THE BASIC PROBLEM OF BOTH INDIVIDUALS WITH DISABILITIES AND OF HUMANITY IN GENERAL: THOSE DANGEROUSLY OBSOLETE PSYCHOLOGICAL AND SOCIAL PATTERNS WHICH ARE OFTEN CALLED STEREOTYPES AND PATERNALISM, AND WHICH INCLUDE A SELF-DESTRUCTIVE OBSESSION WITH POWER AND PRESTIGE THAT RESULTS IN AN OPPRESSIVE, SOCIETY-CRIPPLING COMPETITION AND HIERARCHY. These attitudes and practices are not based on lightly held,

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<sup>3</sup>Center of Handicapper Affairs, A Handicapper Advocacy Alliance, Inc. Agency, 1026 E. Michigan Avenue, Lansing, Michigan 48912

<sup>4</sup>Judy Heumann, Center for Independent Living, Berkeley, California, quoted from Independent Living by Susan Stoddard Pflueger (Washington, D.C.: Institute for Research Utilization, December 1977), p. 1.

It is the right and the responsibility of disabled people (of all oppressed people) to redefine themselves (their identities and their values) as opposed to accepting the definitions imposed by our oppressors.

Bruce Curtis

A new idea--simple, yet wide-ranging in its ramifications--informs our vision of disability. It is that handicapped children and adults are an oppressed minority group. Their oppression takes many forms: outright prejudice against handicapped people of all ages, job discrimination against disabled adults, and well-meaning but destructive misconceptions that exaggerate the true limitations of many handicaps.

John Gliedman and William Roth

easily corrected, conceptual errors resulting principally (only) from poor data, innocent mistakes of logic and out-of-date traditions. They are deadly, passionately held addictions which seem to permeate our conscious and subconscious systems.

Good politics proposes, demands rejection of the stereotyped, subservient roles traditionally assigned to disabled people, and of the tokens, symbols and unfulfilled promises which have for too long been offered in place of full participation in society. Good politics insists on the active assumption by disabled individuals of complete responsibility for and control of their own lives today. Good politics requires specific society-wide action toward equality of opportunity, human dignity and maximal quality of life now.

The fundamental ideological and emotional commitments and the actions implied by "good politics" are what is new about independent living, and what the authors believe should distinguish the authentic independent living and other disability rights movement programs of the 1980s and 90s.

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The movement's dynamic, largely positive activism during the past half century has resulted in rapid symbolic and in-depth progress toward equal opportunity for disabled Americans. As in most periods of pioneer development, our leadership has been almost totally occupied with the execution of action programs, including often frantic efforts to keep up with the opportunity explosion which it helped to ignite. There has been little time for analysis and long-range planning. This choice of priorities could hardly be criticized-- except by comparison to some largely hypothetical example of "perfection." It would, the authors believe, be rather shallow to fault George Washington because he was not also William James, or Martin Luther King because he did not possess all the qualities of Martin Heidegger.



OURS IS ONE OF THE GREAT CULTURES OF HISTORY AND OF OUR TIME--  
BUT ITS VERY SUCCESS HAS CREATED NEW RESPONSIBILITIES WHICH  
MUST, IF WE ARE TO SURVIVE AND TO PROSPER, BE FULFILLED.

Today there are 35 million disabled Americans who represent one of our most underutilized national resources. Their will, their spirit, and their hearts are not impaired, despite their limitations. All of us stand to gain when those who are disabled share in America's opportunities.

President Ronald Reagan

Our nation's commitment to equal protection of the law will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted.

I support federal laws prohibiting discrimination against the handicapped and remain determined that such laws will be vigorously enforced.

President Ronald Reagan

The proposals in this essay, then, carry no implication of indictment. Profound success--along with the passage of time--always brings profound change: new conditions, new challenges, new opportunities and new responsibilities, all of which demand new or modified concepts. The time has come to focus on the philosophical foundations of independent living and the disability rights movement, to clarify and expand basic concepts, to examine present activities in the light of those refined concepts and to chart courses for the future designed to solidify the progress made so far and to lead us toward the achievement of our most deeply held beliefs.

The movement for independent living represents a new chapter in American disability policy. Considering its brief history, the movement's accomplishments in legislation, services and consciousness raising have been truly remarkable. But the movement has only begun. We can expect the movement to reach out to new disability groups and to enlarge its age base as its initial adherents grow older. We can also expect the movement to produce a growing and sophisticated disability literature as it continues to refine its concepts, programs, and services.

Gerben DeJong

## Recent Progress; Current Reality; Future Prospects

Any rational approach to the construction of useful philosophical formulae requires a realistic assessment of the evolving reality in which the concepts will be used.

Dramatic medical, scientific, and social experiments during the past century have demonstrated the potential of many types of individuals with disabilities to achieve a good measure of successful participation in the mainstream of modern society. Forceful, creative advocacy--in combination with a worldwide wave of pro-human rights sentiment--has won popular acceptance of the moral case for handicapped persons. Authoritative representatives of society--the U.N., national, state, and local governments and politicians, the public information media, and individual opinion leaders have formally recognized the problems and proclaimed the rights of people with disabilities.

All this is good. There has been significant improvement in the quality of life of many disabled persons in areas such as education, employment, mobility, and public acceptance. Perhaps more important, the new atmosphere of opportunity and hope, the heightened awareness of individual potential, has encouraged personal initiative and fostered more positive self-images. But does this mean that we are about to achieve our ultimate goal: equal access to the opportunities offered by a society dedicated to the fulfillment of the human potential?

Let us not confuse proclamations and laws with lived reality, or partial, experimental and symbolic success with full and equitable social participation. And let us not confuse "full" or "equal" participation in a troubled and (too often) self-destructive society with that quality of life which rational use of our resources would produce.

Research in the industrialized world . . . is revealing a dangerous trend for social benefit spending which fosters dependence rather than independence among the recipients. . . . Programs to remove barriers to the employment, mobility, and social integration of disabled people are programs which foster independence. Programs to provide disabled people with educational, medical and vocational rehabilitation services are programs which enhance their capacity for self-care and independent living. In nation after nation, expenditures of these types may be relatively small in relation to expenditures which reinforce the dependent status of disabled people: programs of income maintenance and long-term disability pensions sometimes serve as a reward for remaining permanently out of the productive sector of society.

Susan Hammerman  
Assistant Secretary General  
Rehabilitation International

More than three hundred and fifty million people with disabilities live without the help they need to enjoy a full life. They live in every nation, in every part of the world, . . . An estimated Twenty-five percent of the members of any community are prevented by the existence of disability from the full expression of their capacities. This includes not only people who are disabled, but also their families and others who assist and support them. Any society which fails to respond effectively to these problems accepts not only a huge loss of human resources but a cruel waste of human potential.

Charter for the 80s  
Rehabilitation International

It came as a shock to me to realize that one's motivation for action might be considered quite apart from one's moral judgment about the act.

Arthur Lipkin

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Recent estimates indicated that more than 50 percent of qualified Americans with disabilities are unemployed.<sup>5</sup> The figure includes those who, discouraged by repeated rejections, devastating economic and psychological disincentives and offers of obviously unsuitable employment, have "retired" to situations of relative dependency. Almost all disabled persons who do have jobs are significantly underemployed, and 60 percent of working age handicapped Americans exist near or below the official poverty level.<sup>6</sup> Federal, state, local and private disability-related, income-maintenance, medical and direct-service payments--with more than half devoted to the support of non-productive, often counter-productive dependence--have grown from \$59.1 billion in 1970 to an estimated \$210 billion in 1980.<sup>7</sup> If present trends are allowed to continue, this situation, already a major factor in public deficits and inflation, could become an uncontrollable socioeconomic disease.

If these facts are unpleasant,<sup>8</sup> the psychosocial reality which they reflect offers so little hope for the easy solutions which are currently fashionable that the subject is usually glossed over or ignored. The problem of changing society's traditional attitudes, values and methods is the most formidable barrier to the achievement of the goals of independent living. In spite of its widely advertised modernistic, intellectual and democratic

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<sup>5</sup>Newsweek published a 50 percent estimate late in 1980; the Department of Labor recently estimated 60 percent.

<sup>6</sup>Frank Bowe, Rehabilitating America, Toward Independence for Disabled and Elderly People (New York: Harper & Row, 1980), p. 8.

<sup>7</sup>Ibid., p. 6.

<sup>8</sup>Comparable statistics from most other nations would, we suspect, reflect a significantly less adequate social participation by and quality of life for disabled people.

The key to many of our present dilemmas lies in the identification of those social orientations which had great survival value in the past--but which now endanger our survival in the present and cripple our approach to the future.

John McHale

Who is human being? The indifferent and anonymous crowd--tag Man.

Martin Heidegger

Finally, after all the new insights that totalitarianism, nuclear warfare, and mass communication have forced us to face, it can no longer escape us that in all his past man has based much of his identity on mutually exclusive group identities in the form of tribes, nations, castes, religions, and so on. We really suffer from an evolutionary identity problem: is man one species, or is he destined to remain divided into what I have referred to as "pseudo-species" forever playing out one (necessarily incomplete) version of mankind against all the others until, in the glory of the nuclear age, one version will have the power and the luck to destroy all the others just moments before it perishes itself?

Erik H. Erikson

attributes, humanity clings obstinately to primitive concepts and psychosocial structures that have become dangerously obsolete in an age of social and technological complexity, an age which demands sophisticated rationality. Although modern society presents an appearance, a rhetoric of morality, rationality and scientific logic, and declares social justice and quality of life to be its highest priorities, this is at best a reference to isolated experimental successes and secondary characteristics and goals; more generally it is a hopeful, ritual, symbolic expression of unfulfilled ideals. A careful examination of everyday reality reveals that today's society actually operates largely through other values. HOWEVER IT IS DEFINED ACADEMICALLY, SOCIETY--TRADITIONALLY PERCEIVED AS THE TRIBE, GROUP, TOWN, NATION OR RELIGION TO WHICH THE INDIVIDUAL BELIEVES HE OR SHE "BELONGS"--IS FELT AND OBEYED, NOT AS A GROUPING OF INTERDEPENDENT BEINGS (LIKE "ME,") WITH CERTAIN COMMON INTERESTS, NEEDS, AND RESPONSIBILITIES, BUT AS A KIND OF ALL POWERFUL SUPERNATURAL ENTITY, EXTERNAL AND SUPERIOR TO THE INDIVIDUAL, PROCLAIMING ALL GODS AND VALUES, SUBSTITUTING ITSELF FOR INDIVIDUAL LIFE AND FOR LIFE QUALITY AS THE ULTIMATE VALUE. Success in life is felt as the attainment of certain roles in the traditional social drama, and the value of these roles seems to be determined largely on the basis of perceived power and prestige. "The more people I feel superior to (and/or accepted by), the more successful I perceive myself to be." Apparently this system was a valuable tool in more primitive settings--an ingenious device, an unwritten psychosocial constitution, a sort of pro-life religion, which commanded unsophisticated, pre-logic persons to utilize proven, traditional methods and to give first priority to the survival and prosperity of the group, while at the same time engaging in an all out competition which would result in a leadership of the clever and the strong. However, its violence, imprecise communicative methods, crude logic, and overall inefficiency render



. . . what many social critics have perceived as a future threat for society at large has long been a bitter reality for many handicapped children and adults: the disabled already live within a therapeutic state. In this society of the "sick" there is no place for any of the hallmarks of a present or future adult identity; no place for politics, no place for work and sexuality, no place for choice between competing moralities. All political, legal, and ethical issues are transformed into questions of disease and health, deviance and normal adjustment, proper and improper management of the disability.

John Gliedman, William Roth

Surely our great-grandsons will not be wrong if they think of us as barbarians? The truth is that, as children of a transition period, we are neither fully conscious of, nor in full control of, the new powers that have been unleashed. Clinging to outworn habit, we still see in science only a new means of providing more easily the same old things.

Pierre Teilhard de Chardin

The failure to rally around a set of values means that universities are turning out potentially highly skilled barbarians: People who are very expert in the laboratory or at the computer or in surgery or in the law courts but who have no real understanding of their own society.

Steven Muller, President  
Johns Hopkins University

it obsolete and self-defeating in a complex, technological society--and particularly oppressive to persons with disabilities.

Unlike most other minority groups which enjoy certain geographical, cultural, social, physical and communicative advantages that increase their potential to obtain a share of power through traditional methods, disabled people are the weak, the different, the half-pitied, half-despised, half members of every group. IN A SOCIETY WHERE THE ULTIMATE OPERATIONAL (AS OPPOSED TO IDEAL) VALUE IS THE PERCEPTION OF SUPERIORITY TO OTHER PEOPLE, INDIVIDUALS WITH DISABILITIES ARE THE NATURAL INHABITANTS OF THE LOWER REGIONS OF THE HIERARCHY, AND THEY ARE HIGHLY VALUED AS SUCH. Aggressive programs of coercions and disincentives are used to force a majority of disabled individuals into certain traditional, subservient roles: clowns; self-centered, disability obsessed misfits; faithful subjects for weak, insecure mini-mcnarchs; grateful recipients of the good deeds of ineffectual part-time saints; smiling, modest, uncomplaining, thankful Uncle Toms with white canes; sweet Aunt Patsys in wheelchairs--every man's reliable inferiors, society's eternal children. No matter how much of a nothing an able-bodied person is, he or she can always find a disabled person to feel superior to.

Educated to perceive themselves as hopelessly impoverished and permanently outcast from social acceptability and the "good life," millions of relatively silent and invisible disabled Americans live in a state of unspoken, but very real untouchability and millions more live in fear on the edge of that fate. An apparently fortunate, relatively affluent, mostly able-bodied majority struggle unsuccessfully to escape the emerging consciousness that their primitive approach to disability--in combination with similarly obsolete policies in other areas--is undermining their psychological, social and

. . . every year brings us millions more people who are disabled unnecessarily and tens of millions more who are out of reach of any type of rehabilitation assistance. The magnitude of the global problem is practically beyond comprehension: more than 500 million disabled people in the world today of whom at least 350 million live without rehabilitation help of any kind to reduce the limitations imposed by disability in their Catty lives.

Susan Hammerman

economic security and threatening to severely limit, even destroy some of the best aspects of the culture in which their children and grandchildren will have to live.

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The coming decades seem to promise increasingly difficult challenges for individuals with disabilities and their advocates: The unmet physical and psychosocial needs of millions of disabled persons, and the necessity to modify basic value systems and lifestyles in order to meet those needs in lasting, meaningful ways. A fierce competition for resources in a world where the powerful millions insist on expenditures for the wasteful luxuries to which they have become addicted, while the perhaps soon to be powerful non-affluent, ever increasing billions demand the basic elements of physical survival and health, for the able-bodied first, and where a multitude of subgroups, each with its particular power leverage, lobby for all they can get of everything. An entrenched and often hostile social welfare establishment where many institutions and agency personnel have a vested interest in maintaining our current inferior status. A faltering U.S. economy which is aggravated by a rash of confused, often escapist "solutions" and psychologies--and a resulting reduction in funding available for independence oriented rehabilitation. Self-destructive conflict within the movement, and its gradual conversion from self-supporting, self-reliant activism to a state of dependence on establishment funding and the symbols and situations of establishment approval. All of these situations--and others unmentioned--hold the potential of becoming very significant obstacles to the progress of our movement. The latter two problems alone have substantially diluted, neutralized or destroyed many of history's most promising reform programs.

The results of available research do not demonstrate any conflict between the humanitarian basis for rehabilitation service provision and the basic principles of socio-economic planning. Disability will create a cost to society regardless of whether or not rehabilitation services exist. In fact . . . the more a society recognizes these costs, and the more it attempts to ameliorate them through provision of adequate disability prevention and rehabilitation services, the greater is the overall economic return that may be expected.

Study from Department of  
Economic and Social Affairs,  
United Nations

Under conditions of high-speed change, a democracy without the ability to anticipate condemns itself to death.

Alvin Toffler

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This is a grim and uninviting vista. It would appear that both human nature and the tide of history are against the achievement of our ultimate goals. Why should humanity commit a significant portion of its already scarce personal and physical resources to an assault on such apparently overwhelming foes? Has it not survived, indeed progressed successfully through several millennia--always with the oppressed minorities, the impoverished masses, and the disabled at the bottom of the scale--always with idealists issuing futile, "impractical" appeals for social justice? Why must this ancient problem be solved now? Can our society, in the context of the priorities dictated by the current reality, afford to attempt to solve it?

The simple answer, as Frank Bowe has so eloquently stated, "is not only that we can afford to, but that we literally cannot afford not to."<sup>9</sup>

We have constructed a vast, complex psychosocial machine which requires--as a basic condition of its function, definition and self-image--that each member be maintained physically, socially, and politically at or above certain minimum standards. Continuation of our present policy--involving massive, inefficient subsidies which support large segments of the population in relatively idle dependency--threatens to destroy that dynamic, democratic socioeconomic mechanism which has made possible a culture of unprecedented optimism, opportunity and productivity. To revert to the ancient policy of confining severely disabled people to prison-like institutions and back rooms, or simply allowing them to perish would be to cease to exist as a modern, democratic society. The authors firmly believe that if we wish to preserve and expand

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<sup>9</sup>Frank Bowe, Rehabilitating America, Toward Independence for Disabled and Elderly People (New York: Harper & Row, 1980), p. x.

Can there be a change of faith? Here we reach  
the . . . meaning and purpose in human life . . .  
All our ideological ancestors--British Puritans,  
Founding Fathers, French revolutionaries, even  
the Marxists and Leninists--have centered their  
faith on the dignity of man and his ability to  
build the human city. Yet man has remained  
obstinately "tribal" and has used the instruments  
that were to liberate him to maim and destroy  
fellow men wearing another label.

Barbara Ward

the positive aspects of the magnificent cultural experiment which we call America, we must find efficient solutions for the problems faced by people with physical, mental and social disabilities.

The basis of a philosophical approach to these solutions (and to many of man's other self-destructive practices) is well-known, and widely accepted on an intellectual level. It has been openly advocated and experimentally demonstrated by effective persons for thousands of years, but all of our efforts to put it into general practice--including our massive 20th century socialist and social welfare programs--have been significantly frustrated by paternalistic patterns which seem to be woven into the very fabric of our psychosocial beings.

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Given these firmly entrenched psychological, social and (the resulting) physical barriers, IT IS DIFFICULT TO IMAGINE ANY SUBSTANTIAL ACHIEVEMENT OF AN EQUITABLE AND PRACTICAL PSYCHOSOCIAL PARTICIPATION FOR ALL INDIVIDUALS WITH DISABILITIES THAT DOES NOT INVOLVE A SIGNIFICANT RESTRUCTURING OF OPERATIONAL HUMAN VALUES, BASED ON A MORE PROFOUND UNDERSTANDING OF REALITY.



When we . . . rule ourselves, we have the responsibilities of sovereigns, not of subjects.

Theodore Roosevelt

One of the greatest falsehoods spread in recent years is that people are powerless. Far from it.

Henry Grunwald  
Fortune, March 9, 1981

## The Locus and Nature of Responsibility

In his perceptive paper, "The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research,"<sup>10</sup> Gerben DeJong states that:

The independent living paradigm has emerged, in part, as a response to the anomaly of the severely physically disabled person. According to the independent living paradigm the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm ---the dependency inducing features of the physician-patient or professional-client relationship. Rehabilitation is seen as part of the problem, not the solution. The locus of the problems is not the individual but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large. To cope with these environmental barriers, the disabled person must shed the patient or client role for the consumer role. Advocacy, peer counseling, self-help, consumer control and barrier removal are the trademarks of the independent living paradigm.

The authors believe that this is, in the context in which it appears, an accurate condensation of some of the major emotional, attitudinal and philosophical expressions of the diverse, loosely related, elements which currently constitute the independent living movement. It is, in that sense, a true and entirely useful, philosophically meaningful focus. The writers also believe that DeJong's analysis points up the need for a serious effort to clarify and deepen the movement's basic concepts and goals. Additional focuses are necessary.

The attitude that "The locus of the problem is not the individual but the environment which includes not only the rehabilitation process but also the physical environment and the social control mechanisms in the society-at-large."

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<sup>10</sup>Gerben DeJong, The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research (East Lansing: The University Centers for International Rehabilitation, Michigan State University, March 1, 1979), pp. 60-61.

. . . man being condemned to be free carries the weight of the whole world on his shoulders, he is responsible for the world and for himself as a way of being . . .

If therefore I have preferred war to death or dishonor, everything takes place as if I bore the entire responsibility for this war . . . I did not have any excuse; for as we have said repeatedly in this book, the peculiar character of human morality is that it is without excuse. Therefore it remains for me only to lay claim to this war.

Jean-Paul Sartre

reflects, in our opinion, a step forward from the traditional attitudes. It is an understandable reaction to certain aspects of the social system and its physical products which have historically been accepted as more or less natural conditions, but which are now perceived as injustices. It reflects a normal development in a movement struggling toward adulthood. Like many expressions based on emerging understandings, it is true in a partial, technical sense, but does not provide the type of comprehensive focus which could serve as a profoundly utilitarian guide for action. A more mature movement, one capable of effecting the changes necessary to the achievement of its ultimate goals, will focus on the reality that the individual is in one vital sense (in terms of his perceptions) the whole of his environment, and at the same time is an integral part--the perceptual center--of an immense cause and effect unity involving the individual, society, and the universe, which he can control only slightly, but for which he is, for the purpose of maximizing quality of life, totally responsible.

With this concept as the base, IT CAN BE UNDERSTOOD THAT THE INDIVIDUAL WILL BENEFIT BY ADOPTING A WORKING HYPOTHESIS THAT HE IS THE LOCUS OF THE PROBLEM AND THE SOLUTION IN THE SENSE THAT HE IS, WITHIN THE REALITY OF HIS CONSCIOUS UNIVERSE, THE ONLY ONE WHO CAN INITIATE CHANGE AND PERCEIVE ITS RESULTS. THEREFORE, THE INDIVIDUAL CAN BE SAID TO BEAR A COMPLETE RESPONSIBILITY FOR SOLVING HIS OWN AND SOCIETY'S PROBLEMS.

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The individual's total effort to be responsible for himself and society requires him to cease viewing problems as preventable negatives after appropriate remedial action has been taken, therefore eliminating them as personal "failures." For the person in rational control of his perceptions, a

After all, this is a world run by specialists;  
is not that what we mean by a scientific society?  
No, it is not. A scientific society is one in  
which specialists can indeed do the things like  
making the electric light work. But it is you,  
it is I, who have to know how nature works. . . .  
We are nature's unique experiment to make the  
rational intelligence prove itself sounder than  
the reflex. Knowledge is our destiny. Self  
knowledge, at last bringing together the  
experience of the arts and the explanations of  
science, waits ahead of us.

Jacob Bronowski

O God, give us serenity to accept what cannot  
be changed, courage to change what should be  
changed, and wisdom to distinguish the one  
from the other.

Reinhold Niebuhr

problem will be defined, if not always felt, as a preventable negative, a "failure," only so long as he thinks he has an unfulfilled personal potential to solve it. When he believes he has achieved, at least for the present, a maximum effort to effect a solution, it will cease to be a problem in the sense that it will have been reduced to the status of a natural, although possibly "unpleasant," phenomenon such as cold winter wind or death at age 90--a situation to be addressed, but not lamented. Our present reluctance (or lack of effort) to focus on this vital destination between resolvable and (presently) unresolvable problems, in combination with our primitive fascination with miraculous, instant solutions, costs us dearly. "Failures," both active and passive, to accomplish the probably impossible result in terrible burdens of frustration and guilt, an enormous waste of resources, and vast areas of solvable problems which are consistently neglected.

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The immediate goal of independent living, then, is to assist individuals in their efforts to become as physically, psychologically, intellectually, socially and economically responsible as possible. Such persons will actually become, in a very real sense, "independent." To say that a person is not "really" independent because he would be more independent if society were different in certain ways, or that he has not "really" changed his environment much, because his progress has fallen far short of some hypothetical ideal, may be accurate as abstractions, and useful for some types of planning processes, but is not much more significant than saying that 90 years is not really a long life because under certain hypothetical but presently unattainable circumstances the average person could live to be 150.

"I just figured no one was going to like me unless I had money or was famous," Stodghill said last week before being jailed in Austin.

Austin American-Statesman  
December 7, 1981

My dignity is sewn  
Into the lining of a three-piece suit.  
Stiff, and with the whiteness which  
Out-Europes Europe.

Lewis Nkosi

FLAUNTING WEALTH  
IT'S BACK  
IN STYLE

U.S. News & World Report  
September 21, 1981 Cover

## Quality of Life

Independent living and disability rights movement goals tend to be expressed largely in terms of legislation, jobs, funding, housing, transportation, attendant care, physical and financial independence, legal/moral rights and "equality." It is necessary to focus on these areas, but we do not believe that any thoughtful student of our society would seriously argue that achievement of these aims necessarily constitutes the most desirable state of "independence," or of quality of life--or even that it necessarily constitutes an improvement over the reality and potential of an appropriate jobless, institutional, sheltered or homebound situation for certain persons.

It would be a tragic error for disabled people (who can least afford such extravagance) to join the frantic, undisciplined pursuit of fashionable symbols of the "good life" which seems to have infected almost every modern culture. The uncritical acceptance of unrealistic, often unsatisfying or unreachable goals has a devastating effect on the individual and the society. When a positive self-image is defined as being dependent on achieving that which cannot be achieved or maintained--or cannot be maintained without requiring self-defeating sacrifices--waste, frustration, unnecessary subjugation to authority and a lowered overall quality of life result. Instead of becoming more independent, the individual becomes self-destructively dependent, much the same as does a drug addict, or the person in a developing area who is influenced to give up a relatively fulfilling and secure "primitive" culture in order to acquire and affect certain symbols of modernism which are frequently beyond his or her grasp, and often unsatisfying if achieved. Millions of financially advantaged, able-bodied, mainstream Americans--living in one of history's least restrictive, most egalitarian and technologically



What sphinx of cement and aluminum bashed open  
their skulls and ate up their brains and  
imagination?

Moloch! Solitude! Filth! Ugliness! Ashcans  
and unobtainable dollars! Children screaming  
under the stairways! Boys sobbing in armies!  
Old men weeping in the parks!

Allen Ginsberg



Mr. Wildmon is a minister and has a stated set of values; I am a broadcaster and do not.

Gene Mater  
CBS Standards and Practices  
Austin American-Statesman  
June 26, 1981

The commonplace that mortality is not universal, but is relative to time and place, strikes the untutored mind as an assertion that there is no morality at all . . . the right understanding of relativism must lead not to greater laxity everywhere, but to greater firmness in moral intention, greater precision in intellectual, greater subtlety in esthetic.

Jacques Barzun

There are common sentiments, common ideas, without which, as has been said, one is not a man.

Emile Durkheim

There are many classes of change in a person's life which, unlike those based on his tastes, are not person-relative at all, but are favorable changes in his life quite independently of his tastes. Thus, whatever his tastes may be, providing him with nourishment and shelter is making a favorable difference to his life, robbing him of it an unfavorable difference.

Kurt Baier

are "onto logically subjective and can no longer be credibly grounded in a scientific picture of objective nature," that quality of life is a rather vague concept, about which basic issue agreement is difficult or impossible. There are, of course, some truths here, in regard to certain value problems. Reasonable people disagree on secondary values, such as what type of clothes, what type of sex, what type of education, what type of foods and drugs, what type of economy and social structure will lead to the maximum enjoyment of human existence. But are there no universal values?

Look beyond the labels and the rhetoric to the psychological and action content of human being. Observe human beings living and feeling the minutes of their days. Consider the nature of conscious being and interdependent society. One is compelled to conclude that there are values common to all people at this time, that there is a potential unity of undisputed value goals gathering around the concepts "life" and "quality of life."<sup>11</sup> However these values seem to be almost hopelessly fragmented, lost among the myriad jargons, symbols, myths and doublethink mechanisms which inhabit the baroque maze of our still largely primitive consciousness,<sup>12</sup> and relegated to the margins of focus by our excessive concentration on the superficial demands of society.

Humanity needs a new word/concept to express its fundamental, pro-life purpose as a unity. The authors offer this preliminary proposition:

THERE ARE VALUES INHERENT IN THE VERY NATURE OF LIFE ITSELF, OF HUMAN BEING AND ITS INTERDEPENDENT SOCIETY--VALUES WHICH ARE COMMON TO EVERY MODERN CULTURE--VALUES WHICH ARE AGREED UPON BY ALL HUMANS REGARDED AS SANE.

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<sup>11</sup>Philosophers who argue that the human world may be an illusion or that there are no credible universal values are invariably observed to eat regularly and to defend their right to do so.

<sup>12</sup>While our present consciousness clearly reflects more sophisticated and potentially efficient organization than that of previous ages, it is still, to a large extent, primitive relative to our claims of rationality, of living an age of science.

. . . under certain conditions certain moral judgments are objectively true and others are false. That is to say, there are certain moral truths that do not at all depend on the personal idiosyncrasies or cultural perspective of anyone but would be affirmed by any rational agent apprised of the relevant facts.

Kai Nielsen

The provision of a useful vocabulary must be regarded as an important contribution to the demystification of value discussion.

Alvin Toffler

The aim of our argumentation is to emphasize that all experience, whether in science, philosophy, or art, which may be helpful to mankind, must be capable of being communicated by human means of expression, and it is on this basis that we shall approach the question of unity of knowledge.

Niels Bohr

If we split the world up in order to gain detailed knowledge of it, at some point we have to put it together again in order to understand it.

Robert M. Hutchins

ESSENTIALLY, THESE ARE VARIOUS FOCUSES ON THE BASIC PRO-LIFE PROCESSES, THE EFFORTS TO SURVIVAL AND QUALITY OF LIFE. THESE SELF-EVIDENT VALUE GOAL TRUTHS ARE GATHERED TOGETHER INTO A UNITY UNDER THE TERM: QUALITY OF LIFE--OR LIFE QUALITY. The authors submit that the solutions to the majority of humanity's great problems lie within the area of this agreement, this unity. Life quality is, for example, but only in part: survival; living and causing to live; not dying and causing to die. Good health, not sickness, pain and premature death. Eating well, not starving. Being well clothed and sheltered, not injuriously exposed to the elements. The full physical and aesthetic enjoyment of all the senses, not the feeling that one is confined to half-living and surrounded by ugliness. Having a relatively good self-image, identity, feeling oneself to be responsible, productive, a fully contributing and participating, a fully accepted and respected member of society, not alienated, inferior, dependent, a social parasite, a failure. Feeling and causing to feel free, loved, joyful, approved; not unfree, unloved, sad and rejected.

Life quality includes all of these, and an infinite number of other focuses on the universally agreed upon pro-life processes, which could be communicated in an infinite number of ways. But it must, in order to fulfill its basic function as a practical guide for action, differ from these partial value expressions. THE LIFE QUALITY CONCEPT CANNOT BE USEFULLY, COMPLETELY REPRESENTED BY ANY ONE OR NUMBER OF ITS PARTS. IN ORDER TO SERVE ITS PURPOSE, LIFE QUALITY MUST BE CONSIDERED AND USED ALWAYS AS A COMPLETE AND CONTINUALLY EVOLVING UNITY. Our universe and our life in it (or as it) is a continuum in which each action/being affects each other action/being, producing a neverending process of change; a new universe at every instant. But our traditional ways of knowing, deciding, acting, valuing have tried to ignore and/or artificially

We have forgotten what features of the world of experience caused us to frame (pre-scientific) concepts, and we have great difficulty representing the world of experience to ourselves without the spectacles of the old-established conceptual interpretation. There is the further difficulty that our language is compelled to work with words which are inseparably connected with those primitive concepts.

Albert Einstein

As has been said so often, the crisis of our age is a crisis of value. There is little hope of creating new social entities which shall be more stable than the old until new, wider and more complex relationships can be built upon values that are not only generally recognized and deeply felt but that also have some scientific warrant . . . Some values appear to be as much "given" by nature as the fact that bodies heavier than air fall. No society has ever approved suffering as a good thing in itself--as a means to an end.

Clyde Klukhohn

reshape this reality. Now, if we are to begin the age of science lived, we must accept the real nature of our humanity and our ecology, not only in theory, but in action.

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There are undoubtedly innumerable useful ways to communicate the personal and social implications of life quality as the central purpose of human existence. The authors suggest that among these is the following revision of the familiar passage from the U.S. Declaration of Independence: EVERY INDIVIDUAL IS ENDOWED BY THE FUNDAMENTAL NATURE OF HUMAN BEING AND ITS INTERDEPENDENT SOCIETY (AND/OR BY THE CREATOR OF THOSE PHENOMENA) WITH THE UNALIENABLE RIGHT AND THE UNALIENABLE RESPONSIBILITY TO BE MAXIMALLY PRODUCTIVE IN TERMS OF THE PSYCHOLOGICAL AND MATERIAL COMPONENTS OF LIFE QUALITY FOR THE CONTINUUM WHICH IS I, SOCIETY, AND NATURAL UNIVERSE.

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The authors believe it obvious that the great majority of people today do not base their life action decisions on the universally agreed upon life quality values. If their decisions and actions were the result of a careful consideration of their own survival and happiness, of rational, scientific analyses of personal, family and social consequences in terms of direct minute-to-minute perceptions of life quality, how many individuals would go into cold sweat debt to buy fashionable automobiles, jewelry and other extravagant, often dangerous, symbols of social prestige/acceptance instead of investing in that pleasant, peaceful daily life, that relatively secure, affordable foundation of comfortable shelter, enjoyable healthy food, good basic medical care and creative social and aesthetic experience which a properly managed ecology would easily yield? How many individuals would support or acquiesce in the conduct of aggressive war, or



I want . . . to rebuild in man's image what has been built and destroyed too many times over in the witness and image of a foolish and irrelevant God.

Raymond A. Mungo

All his life long this being will be attempting to reconcile these two modes of becoming, the tribal and the personal: the one that makes him into a mirror, the other that lights the lamp of individuality within.

Gordon W. Allport

activities which resulted in the waste, the poisoning of the food, the water, the earth and the air that they and their heirs need to survive? How many people would decide to have so many children that some or all of them will almost certainly suffer serious deprivation, perhaps starvation? How many would choose to grow tobacco instead of grain when their parents are suffering from lung cancer and their children from malnutrition?

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WE MUST GROW BEYOND OUR CHILDLIKE, BLIND WORSHIP OF A PRIMITIVE CONCEPTION OF SOCIETY AS SUPER-GOD, AND TOWARD A MATURE ACCEPTANCE OF THE OBLIGATIONS PLACED UPON US BY THE FUNDAMENTAL NATURE OF INDIVIDUAL HUMAN WILL AND CONSCIOUSNESS, AND OF INTERDEPENDENT HUMAN SOCIETY. WE MUST GIVE UP OUR PRESENT OBSESSIVE PURSUIT OF THE SYMBOLS OF SOCIAL STATUS AND ACCEPTANCE, AND LEARN TO LIVE FOR THE ONLY RATIONAL GOAL OF HUMAN EXISTENCE--FOR DIRECT PERCEPTIONS OF LIFE QUALITY, FOR QUALITY OF CONSCIOUSNESS. WE--BEGINNING WITH THOSE OF US WHO HAVE DISABILITIES, WITH "MYSELF"--MUST ACCEPT COMPLETE, CONSCIOUS RESPONSIBILITY FOR OUR OWN LIVES. WE MUST CONTROL AND MOLD OUR THOUGHTS AND ACTIONS TOWARD A TOTAL, RATIONAL EFFORT TO MAXIMIZE QUALITY OF LIFE FOR THE SELF AND FOR ALL. WE MUST WORK TO DEVELOP A SOCIETY CHARACTERIZED BY AN EQUITABLY, EFFICIENTLY PRODUCED, DISTRIBUTED AND UTILIZED QUALITY OF LIFE, RATHER THAN BY A SELF-DESTRUCTIVE PURSUIT OF POWER AND PRESTIGE. We must learn to employ the sophisticated rationality which our culture demands--including an understanding that success consists not of achieving stereotyped situations of constant trouble free happiness--which probably exist only in storybooks and illusion--but of the responsible utilization of all personal and environmental resources in the eternal minute-to-minute struggle for survival and quality of consciousness. We must face the reality that productivity can be meaningfully measured only in terms of life quality--and that real progress occurs through (usually gradual) changes in the daily thoughts and actions of individuals as opposed to mythical instant utopias effected by "great leaders," "government," and "society." We must be prepared

The Independent Living Research Utilization Project at TIRR has made a substantial effort to distill from published literature and from personal contacts with leaders in the field a concise statement of what independence means in the independent living movement. The answer seems to include two essential elements: 1) assuming responsibility for directing one's own life, and 2) participating actively in the day-to-day life of the community. These two elements constitute fundamental goals of the services provided by all successful independent living programs.

Jean A. Cole  
"What's New About Independent  
Living?"

to do battle, not for one "international year," or for one decade, but for generations, and not with movie style villains, but with the powerful, obsolete psychosocial patterns which exist in the consciousness and actions of us all and with the awesome psychological and physical forces which seem to be permanent characteristics of the human universe.

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THE ULTIMATE GOAL OF INDEPENDENCE, OF INDEPENDENT LIVING PROGRAMS, OF ADVOCACY AND COMMUNICATION--OF THE DISABILITY RIGHTS MOVEMENT IS THE CONSCIOUS ASSUMPTION BY EACH HUMAN BEING OF COMPLETE RESPONSIBILITY FOR HIS OR HER EXISTENCE, AND A FULFILLMENT OF THAT RESPONSIBILITY WHICH RESULTS IN MAXIMAL PRODUCTIVITY IN TERMS OF LIFE QUALITY FOR THE SELF AND FOR SOCIETY AS A WHOLE. The essence of independence--of human fulfillment--and the foundation of equality is not the granting of rights and benefits by others, but the establishment of self-discipline and self-reliance: responsibility for and control of one's own thoughts and actions, and therefore of one's physical and psychosocial independence and quality of life within the limits of a given environment. A Gandhi, an Ed Roberts, a Lex Frieden is unconquerably independent and successful in a jail, a respirator or a wheelchair.

But are not the authors emphasizing patience, individual responsibility and productivity at the sacrifice of individual rights, and the obligation of society to preserve and enhance the quality of the lives of its members now? Are not the authors subtly defending unacceptable aspects of the status quo? The contrary is true. A careful reading of the whole essay will reveal that its central purpose is to focus attention on humanity's vast failures of life quality potential and to urge immediate, dedicated, effective action to remedy those failures as the proper first priority of all people today. The obligations of the individual are emphasized because, unless one subscribes to hypotheses which in terms of present scientific knowledge would have to be called

We must make a transition--and, for better or worse, we are already making it--from an authoritarian and fragmented world to a multi centered and coordinated one. The problem of the young is principally that they consciously reject and refuse to adjust to the old world, and find it difficult to invest the new.

There is a law of interdependence which we must explore in all its ramifications. In its most obvious and crudest form it might be stated as follows: "The health of an organism depends on the capacity of its-various organs to serve each other in a system of interdependence." Not the least of its corollaries are: "The life or death of the entire organism depends on the functioning of each one of its parts," and "Every part of an organism can influence the entire organism."

Danilo Dolci

super-natural, there is no way for society to improve until the people who are society act fulfillment of their unalienable responsibilities to life. The very nature of human consciousness and existence dictates that social change can occur only through mental/physical action by the perceiving "I." In terms of primary perception/action, "society" and "others" are abstractions; only "I"s--individuals--exist in the sense that there is power to decide on and take action which will result in real change. Thoughts and statements to the effect that "society" or "others" should change, should provide benefits, unaccompanied by appropriate action on the part of the advocate, constitute that type of ritualistic expression which has been part of the mainstream social drama throughout recorded history, and which apparently has had very limited power to effect life quality change. Arguments for human rights and other social benefits which neglect or oppose individual responsibility for life quality productivity are, regardless of the proponent's intent, to a large extent reenactments and (in some ways) reinforcements of the status quo. THE ACTION CONTENT OF HUMAN RIGHTS AND SOCIAL BENEFITS IS INDIVIDUAL RESPONSIBILITY FULFILLED.

Of course an Ed Roberts would enjoy a far better quality of life in a society which took reasonable measures to give him maximal opportunities for physical, economic and social independence. And the basic requirement for the existence of, the development of such a society is responsible, self-reliant, self disciplined, activist individuals like Ed Roberts, who are able to establish themselves as the fundamental units--centers--of life quality productive thought and action.

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As the movement's philosophy matures, it will be recognized that employment, housing, transportation, personal care, legal equality and the like are methods and intermediate sub-goals, not final goals--and that the central concern of

The women's movement found it necessary to "raise the consciousness" not of men but of women. Perhaps that is something our movement needs: we need to help others with disability accept responsibility for themselves and their fates, to act rather than react, and to live lives that give the lie to the myths.

Frank Bowe

independent living programs and the movement should become the life quality development of staff, clients, members and public.<sup>13</sup> It will also be seen that when we demand equality, integration and mainstreaming, we are not referring simply to equal participation in the mainstream of our current society. We refer rather to that optimally fulfilling involvement in a society that, in the process of eliminating and replacing the obsolete psychosocial patterns which are the basis of the major (resolvable) problems of disabled people and of all humans, will have evolved into a life quality efficient wholeness.<sup>14</sup>

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Results of preliminary experiments encourage the authors to believe that there is a real potential for proponents of today's most prominent socioeconomic, political, and religious ideologies to agree on the basics of the refined definitions outlined in this paper--and that such agreement could have historic significance.

Widespread understanding of the actual (operational) nature of our present psychosocial structures--and acceptance of maximal productivity in terms of the psychological, material and economic components of quality of life for self and for society as the central purpose of individual and interdependent human



existence--could be the foundation for a bypassing and a withering of many types of traditional disputes among people. New areas of cooperation among nations, groups, and individuals would be possible and--provided that human beings are not terminally addicted to conflict for its own sake--so would be a basis for substantial solutions for many of today's most serious problems.

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<sup>13</sup>Len Sawisch, Lex Frieden, Judy Heumann, Gerben DeJong, Frank Bowe, Bruce Curtis, Pat DuFort and others have made statements which imply thinking in this direction, and the Arkansas Rehabilitation Research and Training Center manual offers a section on the psychosocial aspect of ILP operation.

<sup>14</sup>This particularly significant focus has been expressed by Lex Frieden.

And when one day our humankind becomes full-grown, it will not define itself as the sum total of the whole world's inhabitants, but as the infinite unity of their mutual needs.

Jean-Paul Sartre

It would be understood that the high priority which all people place on achieving symbols of power, prestige, fashionability and social approval-- and the tendency toward unquestioning acceptance of the perceived will of "society"--have frustrated most of the apparently logical modern programs designed to effect just and efficient organizations and societies. General investigative and educational focus on this problem, and appropriate efforts to conform organization to the real nature of human motivation, could result in highly productive combinations of the best elements of traditional, democratic, and socialist theory. Cooperative efforts in areas of potential life quality agreement such as population control, food production/distribution, health, housing, and resource conservation could have dramatic positive effects in a relatively short period of time. The resulting understandings and improvements in perceived quality of life could make the prospect of war increasingly unattractive.

It would be understood that every human being is inescapably not necessarily efficiently) employed 24 hours each day in the production of life quality; that a severely disabled person who chooses to perform certain personal and domestic and other "non-commercial" functions, instead of having those things done by an institutional staff, a family member, an attendant, a social service provider, a business, or a medical professional, may be producing a substantial economic benefit for society and a greatly improved quality of life--and that he or she may very well be more productively occupied in such activities than if the person, family, or community paid for attendants, vehicles, fuel, office overhead, and so forth to create a traditional "job.--<sup>15</sup>

It would be understood that investments in communities, public buildings, homes, and technology which eliminate unnecessary expenditures of time, materials, and energy on the activities of daily living, would be just as productive and

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<sup>15</sup>The authors are not, of course, opposed to independent choice and productive employment; they are opposed to the automatic imposition of stereotyped solutions/ goals which, in certain circumstances, result in non-productive employment, reduced quality of life, and perceptions of failure.

The wise man will give up a lesser  
pleasure to obtain a greater joy.

The Dhammapada

businesslike as investments in modern automated factories.<sup>16</sup> And it would be understood that investments which provide jobs and "profits" in one sector, but create more expense in another, and/or have a neutral or negative impact on the overall quality of life, are not really productive at all. Certainly IBM would not allow one of its divisions to engage in operations which showed \$1,000,000 annual profit, if those operations cost other divisions \$2,000,000. The suggested definition of productivity would simply help society (and IBM) to make the same type of judgments in terms of its most profound values--of its best long-term interests.

Without claiming that they would soon acquire the same personal taste in symbols and life styles, the clarified concepts suggested by the authors would make it possible for reasonable capitalists, socialists, and utopians to agree that any human investment, whether of money, time, material resources, or emotion, must finally justify itself in terms of actual/perceived quality of life.

THE NET IMPACT OF AN ACT ON THE TOTAL BALANCE OF LIFE QUALITY IN THE CONTINUUM WHICH IS THE SELF AND SOCIETY IS THE ONLY TRUE MEASURE OF ITS PRODUCTIVITY--THE ULTIMATE "BOTTOM LINE."<sup>17</sup>

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<sup>16</sup>Efficient investments of this nature would be productive not only in the sense that they made life more pleasant for all, but also in the more traditional sense that public deficits, inflation and taxes could be significantly reduced; that public, business, and private profits would be vastly improved; and that certain ecological and resource crises, including a dangerous over-dependence on foreign sources of supply, could be substantially resolved.

<sup>17</sup>This is not a radical or utopian concept--it is simply a statement of common sense fact. If monetary profit alone were the final measure of value, not too Many people would maintain private flower gardens.

Every man is the lord of a realm beside  
which the earthly empire of the Czar is  
but a petty state, a hummock left by the  
ice. . .

Henry David Thoreau

The cabin by Walden pond . . . was . . .  
ten feet wide by fifteen-long, with a  
garret, a closet, two windows, two trap  
doors, one door to the outside, and one  
fireplace. It cost him in materials  
exactly twenty-eight dollars, twelve and  
one-half cents, and it was certainly  
worth the money, . . .

Joseph Wood Krutch  
Henry David Thoreau

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With values in life-serving perspective, then, it would be understood that for some individuals, establishment in a group living, institutional, or family care setting with significantly increased ability to control his or her own perceptions and existence can be considered a successful result of independent living services and education--a more successful result than placing the person in a conventionally "independent" setting. Life in a 10 x 10 room on an institutional or poverty level budget could be experienced as helpless, hopeless purgatory, a circumstantial prison constructed by uncontrollable outside forces--something to be endured, complained about and escaped from. Or it could--without in any way endorsing it as an ideally adequate or ultimately justifiable situation--be perceived as an opportunity to create a mini-universe of exceptional beauty, a personally satisfying and socially valuable productivity, an eloquent advocacy for self-reliant responsibility for life.<sup>18</sup>

DEVELOPMENT OF THE ABILITY TO EXERCISE EFFICIENT CONTROL OVER THE VARIABLES IN ONE'S ENVIRONMENT AND PERCEPTIONS IS THE KEYSTONE OF THE INDEPENDENT LIVING PROCESS.

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<sup>18</sup>There is strong evidence that institutional living does not have to be unpleasant. Successful people often pay more than \$200 per day for the privilege of living in an institutional setting with 10 x 10 private quarters--for example on a cruise ship.

. . . the minimum combination of services that will provide for the wholistic needs of most severely disabled people should be: information and referral, attendant referral, housing referral, financial benefits counseling, and peer counseling. . . . But an ILP should be more than just a services provider. It should also try to change the environment that disabled people live in. If the prejudiced attitudes are not changed, the bureaucratic red tape removed and the physical and communicative barriers eliminated, the services will help but a few people. If the ILP should in the future ever close, that community should be a better place to live for disabled people because of that ILP's advocacy.

Seventh Institute on Rehabilitation Issues  
"Implementation of Independent Living  
Service Centers in Rehabilitation"  
San Antonio, Texas  
June 3-5, 1980



## The Independent Living Program

We in the movement have undertaken to establish opportunities for disabled people to attain psychosocial and physical independence, equality, human dignity and maximal quality of life--not as superficial labels, symbols, rituals, promises, and hopes for the future--but as livable realities "today." We insist that it is time to move beyond traditional paternalistic, social and rehabilitation structures, and to assume responsibility for and control over our own rehabilitation and lives.

It is vital to remember that the basic objective of the independent living movement--and of any independent living programs--is to accomplish these goals by whatever method is appropriate within the context of particular lives and communities. Therefore we should be wary of approaches and definitions which require inflexible adherence to certain forms and fashions--specific services and methods of service delivery, positions on transient issues and personal, communicative, administrative and organizational styles. As circumstances change, we must be prepared to add, eliminate, and/or modify services, service delivery methods and other policies. Under any circumstances, our primary activity must always be that which seems most likely to effect the desired changes in human values and actions.

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The authors believe that the philosophical foundations and long-range goals outlined in this essay will best be achieved not by the evolution of the independent living movement into a massive cluster of government and/or private service provider agencies, or by focusing only on certain narrowly defined interests of particular disabilities, but rather by developing a complex of self-reliant, (preferably computer connected) broad scope

Use an existing service first. Encourage the development of appropriate services in existing agencies. Hopefully we will work ourselves out of a job.

Paula McElwee, Director  
Program Services  
Developmental Services of  
Northwest Kansas

Independent living programs should not duplicate services offered by other agencies but should attempt to provide only those services which are lacking in the community.

Brenda Premo  
Executive Director  
Dayle McIntosh Center  
for the Disabled

independent advocacy oriented entities. These programs would provide extensive systems of relatively conventional services essentially as a movement building device and a transitional how-to-do-it demonstration. They would strive for maximum utilization and development of outside local, state, and national resources, and minimum investment in staff and physical facilities, minimum expense, and minimum involvement in relationships which result in restrictive regulations. They would aim toward eventually integrating their basic concepts and practices, and a large percentage of their key personnel and successful clients into the determining processes of cultural development: family; education; the information and entertainment media; governmental and commercial administration; the sciences, including medical, rehabilitation, social, psychological, and self-development services and techniques; planning and construction; agriculture; the arts and so forth. It is important to note that the need for an independent, experimental and socially/politically effective advocacy oriented movement will not cease soon; so long as human life and culture exists in something like its present form, there will be new challenges at the frontiers of life quality.

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It is generally agreed that there is a present need to provide certain services to disabled people and to demonstrate the feasibility of certain policies in regard to service delivery.

Bruce Curtis states that:

A functional ILP has a minimum of five service areas: attendant referral, housing referral, peer counseling, financial benefits counseling, and information/referral.<sup>19</sup>

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<sup>19</sup>Bruce Curtis, How to Set Up an Independent Living Program, Twenty-seven Questions and Answers (Houston: ILRU, May 1980), p. 10. These services meet the requirements of an active ILP established by the California Coalition of Independent Living Projects and the national advisory board and staff of Independent Living Research Utilization.

The most important aspects of independent living services are: 1. Peer counseling; 2. Role modeling, it is important to have appropriate disabled staff who can serve as successful role models; 3. Attendant care, an area of critical importance in making independence possible.

Max Starkloff  
Executive Director  
Paraquad, Inc.

In order to begin changing the way services have historically been given to disabled people, it is necessary that disabled people themselves have control over the prioritization and delivery of services. . . . Non-disabled people can only have an intellectual approximation of the needs of disabled people. Therefore, their intellectual analysis combined with their tendency for discrimination and paternalism, has often led to insensitivity and distorted priorities in the delivery of services to disabled people. . . . Hiring a disabled director makes a statement to the community that disabled people are competent, productive, creative, and capable leaders.

Bruce Curtis

The mentioned services are characteristically offered in a non-residential setting.<sup>20</sup>

These are practical guidelines which seem quite appropriate for many areas and situations at this time, but it is not difficult to envision circumstances which would require more or less or different types of services--and, of course, personnel requirements and the nature and scope of each type of service would vary at least slightly for each program. The authors feel that during the 1980's it would be difficult for any organization to claim ILP status that did not offer programs of advocacy, counseling and information and referral which were appropriate to the needs of its particular clientele and target area, or which did not have a substantial proportion of movement oriented disabled persons among its governing and executive personnel.<sup>21</sup>

IT IS THIS ELEMENT OF ADMINISTRATIVE AND POLICY CONTROL BY PHILOSOPHICALLY SOPHISTICATED DISABLED INDIVIDUALS--PERSONS WHO FULLY RECOGNIZE THE RIGHT AND THE RESPONSIBILITY OF THE DISABLED BENEFICIARIES OF SERVICES TO EXERCISE ADULT

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<sup>20</sup>Limited resources and the overwhelming unmet needs of 35 million disabled Americans make the desirability of non-residential independent living centers obvious. Despite this fact, and a vivid awareness of the paternalistic abuses associated with traditional institutional living, there is a trend toward experimentation with transitional situations. During the 13 years that we have been operating our small private (transitional) program, which includes both disabled and able-bodied people, we have never been able to achieve the type of broad, whole life development which we consider to constitute a responsible fulfillment of personal potential without using a residential setting, or with less than six months residence. Of course our experimental results--involving a relatively small number of individuals with particular types of problems and utilizing a limited number of educational techniques--do not provide any sort of conclusive evidence. But it may be that--using currently available methods--certain well-established psychosocial patterns can be more easily modified in a social milieu which is almost totally supportive of the change. Our understanding of history also seems to support this hypothesis.

<sup>21</sup>It is generally agreed that an authentic independent living program will have a disabled director, and at least 51 percent disabled employees and board members.

Independent living programs should be created, led, and operated by disabled people. The staff should have a good understanding of and a strong commitment to independent living philosophy.

Ingo Antonitsch

DOMINION OVER THEIR OWN LIVES AND TO BE MAXIMALLY PRODUCTIVE IN TERMS OF LIFE QUALITY--THAT IS THE MOST SIGNIFICANT DIFFERENCE BETWEEN THE TRUE INDEPENDENT LIVING PROGRAM AND THE TRADITIONAL REHABILITATION INSTITUTIONS.

In its broadest implications the independent living movement is the civil rights movement of millions of Americans with disabilities. It is the wave of protest against segregation and discrimination and an affirmation of the right and ability of disabled persons to share fully in the responsibilities and joys of our society.

Edward V. Roberts



Toward A More Responsible, Credible, Self-Reliant -  
A More Mature - Movement

IT WOULD APPEAR THAT IN THE EVOLVING SOCIAL REALITY THE VAST MAJORITY OF THE BURDEN FOR EFFECTING THE PARTICULAR SOLUTIONS REQUIRED BY PEOPLE WITH DISABILITIES WILL FALL ON THOSE OF US WHO ARE DISABLED, AND ON THOSE RARE NON-DISABLED INDIVIDUALS WHO HAVE ATTAINED A MATURE UNDERSTANDING OF AND DEDICATION TO THE CAUSE OF LIFE WITH QUALITY. In a socioeconomic system which bestows its most desired benefits upon groups that have organized to play the power game well, in a society which seems increasingly to be characterized by psychosocial forces out of control--by a disorganized, too often escapist, every-man-for-himself competition for and consumption of resources, it seems doubtful that any significant segment of the establishment will volunteer much more than self-serving or ritual support for the cause of equal quality of life opportunities for individuals with disabilities.

In spite of our movement's recent gains and great potential, disabled people remain the nation's and the world's most poorly organized large minority. As long as this situation is allowed to prevail, we and the programs designed to help us will continue to bear the consequences. Even in the best of times, our rights and our welfare will receive low priority attention; in times of scarcity and crisis, we will be among the first to suffer. If we wish to sustain our forward momentum, or even to maintain the positive aspects of our current situation, we must develop a far greater proportion of our movement's potential.

One of the authors is frequently asked, especially by service providers, for advice on how to gain support for a particular program or policy in the Office of the Governor, the state legislature, the Congress, or the White House.

20 MILLION AMERICANS--  
DISABLED,  
BUT ABLE TO VOTE!

Larry Johnson  
Vice President  
Coalition of Texans  
with Disabilities

. . . disabled individuals do have a  
voice in legislative issues when they  
write or phone their congressman. . . .  
now is the time to speak out!

Brenda Premo

There is the implication that a letter or telephone call from an influential person might be the solution. Of course the right "connections" are always helpful, but there is, in the present American system, only one consistently reliable method to ensure favorable public/government action in regard to productive programs: solid grass roots voter/consumer organization and sophisticated advocacy. We must unite--people with disabilities, their families and friends, service providers, progressive business persons, allied social action groups, all those who share our views--in working to change attitudes. We must, as individuals and as organizations, join our local, state, and national advocacy groups and support them with our time and with our money. It is particularly important that we develop organizations such as Coalition for Barrier Free Living (Houston), San Antonio Citizens Concerned for the Handicapped, the California Association of the Physically Handicapped, the Coalition of Texans with Disabilities, the American Coalition of Citizens with Disabilities, the League of Disabled Voters, the proposed national Coalition of independent living programs, and Disabled Peoples' International which have the advantage of representing all individuals with disabilities. Thirty-five million disabled people plus their families, supporters, and service providers form one of the America's largest and potentially most powerful shared interest groups. A consistent, efficient, articulate, morally credible advocacy, backed by 20-30 million informed voters, would contribute enormous power to our movement's ability to achieve its goals.<sup>22</sup>

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<sup>22</sup>Eunice Fiorito, Durward McDaniel, Lex Frieden, Frank Bowe, Judy Heumann, Al Pimentel, Pat Pound, Larry Johnson, Joe Veisz, Bob Cooper, and others have made important contributions in this area.

John Williams: Is it a civil-rights movement?  
Frank Bowe: In early 1977, I would have answered, "Yes." Today, I hesitate a bit. A civil-rights movement is a broadly based, mass movement toward clearly articulated objectives. The disability movement to date is more narrowly based and protectionist, if you will: reactive rather than active. The next few years will tell us if this is a real civil-rights movement or just another special interest.

Up Front  
October, 1981

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OUR MOVEMENT IS INVOLVED IN A LONG-TERM STRUGGLE FOR BASIC HUMAN RIGHTS, NOT A MADISON AVENUE PROMOTION OR AN OPULENTLY FINANCED, HIGH PRESSURE LOBBYING VENTURE. WE HAVE NEITHER THE RESOURCES NOR ANY RATIONAL MOTIVE TO PLAY THE BIG STAFF, CARPETED OFFICE, SPECIAL INTEREST GAME. IN ORDER TO SUCCEED, WE MUST PURSUE A FORM OF ADVOCACY WHICH IS BASED ON FIRM BUT REASONABLE, PRACTICAL DEMANDS; RESPONSIBLE, COOPERATIVE ACTION DESIGNED TO MEET THE REQUIREMENTS OF THE WHOLE SOCIETY; AND ON THAT ADMINISTRATIVE, MORAL, AND PHILOSOPHICAL CREDIBILITY FOR WHICH ALL HUMANITY FEELS A DESPERATE CONSCIOUS AND SUBCONSCIOUS NEED. THE FOUNDATION OF OUR ADVOCACY MUST BE LEAN, TOUGH, FLEXIBLE, SELF-RELIANT, INDEPENDENT INDIVIDUALS AND ORGANIZATIONS WHICH ARE SOLIDLY ROOTED IN AN EFFECTIVE UNDERSTANDING OF REALITY, AND WHICH COMMUNICATE A PROFOUND RESPONSIBILITY FOR THE VALUE OF HUMAN LIFE. As has been seen--through the lives of Buddha, Christ, Gandhi, and many others--there is a mysterious, almost irresistible power connected with the impression that a serious attempt is being made to conform action to the best traditional, universally accepted moral and philosophical ideals. The potential for this power is not limited to a few exceptional groups or persons; its concepts and methods are freely available; it can be achieved to some degree by almost anyone willing to invest sufficient passion, patience and self-control.

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OUR MOVEMENT MUST, IF IT IS TO REALIZE ITS APPARENT POTENTIAL AT ANY LEVEL, DEVELOP CONCEPTUAL FOUNDATIONS, ORGANIZATIONAL RELATIONSHIPS, AND PROGRAMS WHICH ARE MATURE AND RESPONSIBLE IN THE CONTEXT OF THE TOTAL LOCAL, NATIONAL, AND INTERNATIONAL ENVIRONMENTS. THIS PROCESS WILL REVEAL THAT WE HAVE GOOD REASON TO MAKE COMMON CAUSE WITH EVERY HUMAN BEING WHO SUFFERS ANY SIGNIFICANT FORM OF INJUSTICE IN THE PRESENT SOCIAL ORDERS--AND THAT ACCOMPLISHING THIS WILL STRENGTHEN RATHER THAN COMPROMISE OUR EFFORTS TO REACH OUR ULTIMATE GOALS.

. . . the . . . movement, at this stage, needs to recognize universal elements and universal goals common to the human condition. Human beings with disabilities are first and foremost human beings. Their condition is the human condition and their goals in the universal sense are goals of all persons. The cultural and/or social factors which limit the achievement of these universal goals are, in fact, the same factors which limit all humans in the achievement of their destinies.

. . . the disability movement needs to identify with the common struggle of all oppressed people, based on the unique set of commonly shared experiences of their own cultural, social, economic and spiritual oppression. It is an empathetic leap, an argument by analogy, which may allow evolved leaders of the disability movement to rise to the defense and liberation of others through their awareness of the elements of oppression common to all. Without this leap, the movement will inevitably degenerate into a static, self serving and incestuous downward spiral.

Michael Twombly  
Executive Director  
Texas Society for  
Autistic Citizens

We have all been "niggerized" on one level or another.  
And all of us are determined to "deniggerize" the earth.

Stokely Carmichael

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We must expand the scope of our thinking and activities to ensure a more significant understanding of, cooperation with, and participation by all individuals with disabilities, including disabled veterans, and people who are mentally and personality impaired, elderly, chronically and terminally ill, developmentally disabled, and addicted to drugs and alcohol.

There should be a strong, creative focus on community outreach with regard to minority and poverty groups. Minority and poverty area representation in most independent living programs and advocacy groups is poor, particularly at the leadership level. It is sometimes said that a substantial cause of this is the traditional tendency of certain minority and ethnic groups to care for their disabled members through the family structure. This may be true; however the authors do not believe it indicates that most disabled Hispanics and blacks (for example) are living independently and have no need to be involved in the movement. Too often it means that they are residing in back rooms, prisoners of, rather than liberated by, their cultures. We need a disabled Cesar Chavez and a disabled Martin Luther King.

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We must make a determined, long-range effort to establish solid communication and basic-issue cooperation, not only with disability-related groups, but also with consumer-oriented, minority, social action, business, civic, political, and governmental organizations (and individuals) on the local, state, national, and international levels. We must learn to understand their needs, their motivations, their problems--to deal with them as full members of our psychosocial continuum, as potential partners in progress or failure, as opposed to "funding sources," competitors for resources, ill-motivated, reactionary adversaries, or simply non-related "others." The great dangers and corresponding opportunities

Injustice anywhere is a threat to justice everywhere.

Martin Luther King, Jr.



facing humanity--psychological and physical violence; gross ecological mismanagement; an irrational utilization of resources; chaotic, fiscally irresponsible, low productivity economic policies; over-population, exploitation, poverty, famine, pollution, war--are not, as some would appear to think, remote to the concerns of individuals with disabilities, but must be seen as important areas of focus and action for the disability rights movement.

How many thousands of disabled humans die each month for lack of the basic necessities of life which could easily be provided to them? How many are forced to exist in subhuman, social and material circumstances? The authors' experience indicates that an estimate based on appropriate research would be absolutely shocking.<sup>23</sup> Disabled people are always among the first to suffer--and to perish--when human beings fail to fulfill their fundamental responsibilities. If individuals with disabilities really wish to grow beyond their status as humanity's eternal children and to achieve full, adult participation in society, they must be willing to undertake the obligations of such participation. It would seem highly unlikely that the disabled citizens of the United States will be able to attain their ultimate goals until the problems which cause all major forms of injustice and other life quality inefficiency are substantially solved for the great majority of the world's people.

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Absolutely essential to the success of any effort to expand the scope and to communicate the philosophy of our movement will be the placement of qualified, independence-oriented disabled persons in positions of significant

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<sup>23</sup>The October 26, 1981, issue of Newsweek stated that the life expectancy for 3.4 billion citizens of the developing countries was 56 years, as compared to 72 years in the developed countries. This means that about 50,000,000,000 years of present human life--including perhaps 5-7,000,000,000 years rightfully belonging to disabled persons--will probably be lost because the action of our daily lives does not support our declared belief in the value of life and its quality.

Become a source of accurate information for the media, agencies and government; establish credibility. Promote marketable, newsworthy PR; put yourself in the editor's position.

William Tainter  
Executive Co-director  
Community Service Center  
for the Disabled

Look successful, look professional, create and examine communications carefully (letters, grants, press releases, brochures, letterheads, etc.). Give careful attention to positive communication with agencies, government, funding sources, the media; cultivate relationships with reporters, writers, editors; tell the media why independent living is different, why disabled people want to run their own programs. Write thank you letters to media people who cooperate. Use colorful PR methods.

Johanna Wallace  
Executive Director  
Center for Independence  
of the Disabled

responsibility, especially at policy making and administrative levels, not only in programs affecting services specifically for individuals with disabilities, but in all aspects of social commerce. In the context of the present psychosocial structures, no system of government or law can, by itself, guarantee justice to a dependent group. Effective participation in the competition for power is a prerequisite to the achievement of equality.

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As modern, technological society grows more complex, the public communication media assumes an increasingly dominant role, in many respects replacing or controlling through the power of selective interpretation the traditional political, economic and ideological hierarchies. We would be well-advised to give high priority to a community and public relations policy based on visible adherence to principle, patience, positive confrontation, and long-term and cooperative persona and institutional relations. We should advocate for the meaningful involvement of qualified disabled people in all aspects of the public communication process, particularly as policy makers, and as visible actors/communicators in roles which convey the concept that full, responsible social participation by individuals with disabilities is both natural and desirable.<sup>24</sup> Our actions should reflect a realistic, empathetic understanding of the motivations and needs of those individuals who make and influence media and community decisions. We should avoid the constant demands for media coverage and extravagant involvement in currently fashionable issues and exhibitionist activities which are typical of many

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<sup>24</sup>The importance of the modern communication media and proposals for the productive involvement of our movement in the media processes have been articulately expressed by Pat Pound.

Let us suppose that certain individuals resolve that they will consistently oppose to power the force of example; to authority exhortation; to insult, friendly reasoning; to trickery, simple honor. Let us suppose they refuse all the advantages of present-day society and accept only the duties and obligations which bind them to other men. Let us suppose they devote themselves to orienting education, the press and public opinion towards the principles outlined here. . . .

Then I say that such men would be acting not as Utopians but as honest realists. They would be preparing for the future and at the same time knocking down a few of the walls which imprison us today. If realism be the art of taking into account both the present and the future, of gaining the most while sacrificing the least, then who can fail to see the positively dazzling realism of such behavior? . . .

Albert Camus

One danger is that the movement for independent living may underestimate the role of economic power in the political arena. . . . Another danger is that by becoming a part of the political process the movement may become more conservative.

Gerben DeJong

public relations programs today. We simply do not have the financial and power structure resources to compete with Coca Cola or the transportation lobbies on their terms. What we do have is passionate dedication to ideals and goals, the fulfillment of which will benefit all people. Our greatest communicative weapons--if we have the will and the self-discipline to develop and use them--will be the communications, the personal and public relationships which are the natural products of lives responsibly lived.

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The substantial successes of the disability rights movement in such areas as legislation, employment, education, architectural barrier removal, rehabilitation, and independent living render it vulnerable to the temptations of security and status. Although statements of commitment on the part of the establishment and expressions of willingness and intention to change are important steps down the long and difficult road of remolding society, we must beware of accepting symbolic as opposed to substantial fulfillment. Almost all establishments have attempted to appease, to delay, to defeat successful reformist movements by conferring prestigious titles, powers, and benefits on token and/or completely fraudulent individuals and groups as examples of their (the establishment's) "progress," and as the basis for arguments that further concessions would be unnecessary duplications. It is fairly obvious that this tactic is being employed against the independent living and disability rights movement.

Even the most sincere movement people can be subverted by the powerful traditional undercurrents in their own consciousnesses--by their own subconscious adherence to the established psychosocial patterns. The fashionable words and forms of advocacy can easily mask traditional structure and intent; a dedicated, liberal idealist with a disability can be just as power hungry and paternalistic, just as handicapped by stereotypes as a status oriented conservative who is able-bodied. It is easy to point the finger and accuse others of this failing, however everyone, including the authors, is

. . . being disabled is no guarantee of sensitivity.  
As in all oppressed groups, discrimination teaches  
self-hate and instills a deep desire to be a part  
of the privileged class.

Bruce Curtis

Emphasize the continual creation of new leadership;  
keep dividing organizations into more groups and  
subgroups in order to force more members into  
leadership roles. Encourage members to express  
and promote their own ideas in their own ways and  
through their own actions--speaking, writing, singing,  
praying, signing, whatever.

Bob Cooper  
Past President  
Rhode Island Handicapped  
Action Committee

vulnerable to it. Self-deception, rather than conscious conspiracy, has always been the worst enemy of well-meaning human beings. IN ORDER TO CONVINC OTHER PEOPLE TO MODIFY NEGATIVE ATTITUDES, WE MUST FIRST BECOME AWARE OF AND ELIMINATE THE OBSOLETE THOUGHTS, PATTERNS, AND ACTIONS IN OUR OWN LIVES.

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We must cease those self-defeating conflicts over position, personality, style, methodology, and ideological symbolism and those unrealistic demands for instant perfection that have debilitated or destroyed most of history's initially successful reform movements and revolutions. We must somehow conquer the immaturities which generations of oppression have thrust upon us and learn--very quickly--the sophisticated organizational skills that will meet our unique needs.

A first priority will be to develop a much larger and more effective leadership core, one which is able to give adequate representation to 35 million disabled people. Our movement and its constituency has distinguished itself by the exceptional quality of its members, not only the few highly visible spokespersons, but also those extremely able individuals who constitute the broad working base of our mini-nation. There are, in the authors' opinion, significant numbers of persons of the potential of Franklin, Jefferson, Hamilton, Madison, Paine, Madero and Martin Luther King, and many more, probably a majority of disabled people, who have the talent to make less traditionally dramatic but equally important creative and leadership contributions.

We must seek out these individuals and give them appropriate opportunities to develop their skills. We must stop limiting them because they fail to meet stereotyped standards and because we perceive them as threats to our personal ideologies and ambitions. We must learn to modify old forms, definitions, and

To achieve the goals of the International Year of Disabled Persons in 1981 . . . we must, all of us, become full partners in a community effort.

Groups of disabled consumers must learn to trust and understand one another, work in harmony on issues of common vital concern, and play an active leadership role in bringing all sectors of the community together into a cooperative working partnership. No single group can do it alone; and no group must be left out.

Larry Johnson



emotions to mold roles in such a way that the effect of disabilities and areas of inexperience can be minimized and abilities totally utilized. We must master the art of combining creative individualism and efficient cooperation to form a dynamic, complementary, life quality productive unity.

In order to produce the quality and quantity of leadership we need, we must overcome, or at least substantially modify, certain common paternalistic patterns. Most administrators, teachers, and counselors, including disabled persons, characteristically resist any development by employees, students or clients which would tend to give the disciple status equal to or greater than that of the master.<sup>25</sup>

The authors have not, of course, succeeded where Buddha, Christ, Marx, Mao, Bruner and Skinner have failed--to convince human beings to act rationally in their own self-interest. They have however, in the course of developing their 13 year-old private independent living program, discovered a system which can bypass or modify a few of the problems, and sometimes use the power of the traditional patterns against themselves. The leader, the service provider is encouraged to assume the attitude of the best of coaches and attorneys, who tend to measure their status not by the number of employees or clients maintained in subservient roles, but by the extent to which their clients can qualify as "winners" in terms of personal potential fulfilled. The development of an individual who attained a position in society, in the movement, superior to that of the counselor would then be perceived as a

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<sup>25</sup>This problem has long frustrated man's best efforts to develop rational organizations and societies. Some striking recent examples are to be found in the socialist nations, the large corporations, the U.S. social welfare programs, and, unfortunately, some independent living programs.

Life is unfair in lots of places--in Haiti, in Iran, in Japan, in France, in Germany, in Kenya, in Cambodia, and in England. Nowhere is life guaranteed to be fair. And if we happen to be a member of a minority, it is less fair--wherever we are--than for one of the majority.

Less fair means we have to work a lot harder to even up the odds. It means we must determine the nature of the challenge and the cost involved to make progress and to succeed. And above all, we must determine whether or not we're willing to pay that cost. The cost is high, but it's not going to get any lower.

Major General Jerry R. Curry  
"Black Man in a White Man's  
Army" - 1981

status symbol, rather than a threat to position and ego. This process involves a strong emphasis on personal and public recognition for the success of both "coaches" and "players."

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In calling for more unified, sophisticated, self-disciplined approaches to our problems and relationships, the authors do not mean to imply that emotions should be suppressed, but rather that they should be managed, used in such a way that they become factors which are positive to the achievement of our goals. A purely intellectual commitment will not suffice. At this stage of human development great projects seem to require great, but properly disciplined emotions. History seems to indicate that most effective advocates for significant reform have given evidence of benefiting from a consuming but controlled passion for some vision of social justice.

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A good deal of concern--even despair--is currently being expressed by movement people in regard to the lack of requested support for various disability related programs by government and other established trustees of our socioeconomic resources. It is, of course, our obligation to protest, and to advocate responsible measures to remedy any apparent failure of society to maximize the life quality potential of disabled people. But it is also our obligation to be aware of and to deal effectively with the psychosocial dynamics inherent in the tasks which we have undertaken.

We are not participating in a Sunday school discussion or a college debate. Beneath the politely civilized veneer of cordial communication with establishment representatives and meetings in fashionable hotels lies the stark reality of a species engaged in a brutal, apparently permanent struggle for the symbols of power and prestige--a struggle in which abject poverty, physical and psychological violence and (premature) death are so commonplace as to go largely unreported in the daily news.

With the rapid expansion and proliferation of independent living programs, more programs will fail due to over expansion and mismanagement. It is possible that this will lead to an effort by the federal government to impose strict controls on independent living program funding, program standardization or perhaps even licensing requirements. This rapid program development may also lead to the evolution of a type of independent living specialist or professional ILP staff person. If these changes come to pass, the likelihood of institutionalization is inevitable, and the Independent Living Program Movement will no doubt wind up a part of the nursing home establishment, the MHMR establishment, or something analogous to those.

Lex Frieden

Establish a sound administrative structure at the outset with good bookkeeping and accounting. Hire a good director--a person with vision, with the "guts" to fight paternalism and who understands what proper service delivery is. Some work and financial experience is preferable; academic qualifications are not as important. . . . The director should be available for outreach activities and to represent the program in top level funding matters. Develop staff members who are dedicated to the philosophy of independent living and who are ready to work more than 40 hours. Choose board members carefully.

Judy Heumann, Deputy Director  
Center for Independent Living

This savage aspect of human existence has been present throughout recorded history. Those who demand fundamental change, who are perceived as threatening the ideas and structures which support the traditional power hierarchies, have always been opposed by establishments. The ability to be psychologically, socially, and philosophically tough, patient and economically self-supporting--to be self-reliant--is a basic prerequisite for success. Many, perhaps a majority of humanity's most profoundly creative social and intellectual ventures were initiated and maintained for long periods of time under extremely modest socioeconomic circumstances: in back rooms, attics, under trees or in caves, frequently enduring public disapproval, harassment and violent repression by authorities. Experience seems to teach that basic, unadorned survival and simple ideological integrity are two of the most important factors in the establishment of lasting power, that society will eventually accommodate and include individuals, groups, and ideas that simply refuse to "give up."

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We must develop a more effective ability to deal realistically with the problems of finance, economics, administration, politics and productivity. Programs must adopt policies of relative fiscal and administrative conservatism, with increased focus on "businesslike" administration, cost efficient operation, meticulous record keeping (the latter is important in relation to cost control and also in providing protection against the frivolous accusations of wrongdoing which have become fashionable) and above all on quality control--on constant evaluation and refinement in regard to results produced in terms of positive changes in people's lives.

The authors recommend that independent living programs and advocacy organizations devote a substantial portion of their resources--personnel and

A center should be as independent as it wants its handicappers to be. We look on the funding cuts as an opportunity; we will be back to where we started financially.

Lynne Rutledge  
Executive Director  
Center of Handicapper Affairs

The ILP should be community based and consumer operated. Any group that waits to start a center can do it if they believe and work we started with \$67.

Beverly Chapman

Don't make the independent living program so large that it cannot be supported by the community without outside grants.

Bruce Curtis

financial--to the construction of the type of broad, stable funding base utilizing several sources, which would allow maximal philosophical and administrative independence. Possible funding methods include: a well-established, non-restrictive, flexible program of fees for services; inclusion in regular local, state and federal funding programs as permanent social service providers; contracts with businesses, agencies and other organizations for consultation and services; donated office space, equipment and supplies, and eventually private and/or government funding to purchase an appropriate physical plant; practical systems of private fund raising with broad community appeal and specific community, non-staff administrative support; and, most importantly, a strong foundation of financial support provided by regular and capital donations from staff persons, clients, and members a friends of the disability rights movement. The currently fashionable assumptions that a project which does not receive outside funding cannot be started or maintained, or that movement people should not make regular financial contributions to their own programs as church members and business person do, are devastating misconceptions. This type of thinking tends to pass effective control of the program and the movement to outside, generally establishment sources. It is naive to expect the establishment to volunteer permanent financing for significant assaults on concepts and structures which are foundational to its power and perceptions of prestige. Funding cuts would be especially tempting if it seemed probable that such actions would cause the termination of particularly threatening programs or the dissolution of certain activist groups.

The ILP should be structured and budgeted in such a way that it is not necessary to dedicate excessive amounts of money and personnel time to the direct and indirect requirements of outside funding, and in such a way that it can survive

The risk is that new funding could bureaucratize the movement and blunt its cutting edge as it becomes involved in organizational maintenance activities at the expense of advocacy. Moreover, independent living funds may be diverted into activities that are only marginally associated with independent living, thus diluting the meaning of what independent living is all about. Finally, since new funding will come through the Rehabilitation Act, there is the danger that the movement may become captive of the rehabilitation establishment

Gerben DeJong

The challenge, then, is clear: the U.S. must reduce consumption today in order to invest for tomorrow.

Malcolm N. Carter  
Money Magazine, 1981

Get board members and staff persons who are competent, who will work. Include appropriate non-disabled persons. Be prepared for 18-20 hour days. Establish credibility by following through. Don't ever promise what you can't deliver.

Joe Vests, Executive Director  
Leon Center for Independent Living



almost any period of curtailed or terminated funding, public and/or governmental disapproval and ecological or socioeconomic difficulties, operating on a minimum basis with donations of time, material and funds by staff, clients and movement members.

The program's fiscal and administrative philosophy should be characterized by a strong sense of obligation to be a productive component of the whole society. The independent living movement has nothing to gain by entering the current, irrational competition for resources--asking the impossible and taking everything we can get today, with little thought for tomorrow--or for what we are contributing to ourselves and to society. The notion, apparently held by many, that there is something slightly obscene about hard work, efficiency, productivity, profit and broad, day-to-day fiscal and social responsibility--and that "society" should and can provide certain benefits to each human with no corresponding obligation on the part of the individuals who are the society to make this happen, reflect a profoundly confused immaturity. This childish what's-mine-is-mine-and-what's-yours-is-mine ("give me" socialist) psychology infects and seriously handicaps all modern cultures, socialist and capitalist alike. It is enormously extravagant and self-destructive. It almost guarantees a hostile, often repressive backlash reaction by those who perceive themselves as being the hard working core of society. A fragile, infant movement with extremely modest financial resources simply cannot afford it.

NOW IS THE TIME FOR OUR MOVEMENT TO SEIZE THE BANNER OF PRODUCTIVITY.  
EVERY HUMAN BEING HAS BOTH THE UNALIENABLE RIGHT AND THE UNALIENABLE  
RESPONSIBILITY TO BE MAXIMALLY PRODUCTIVE IN TERMS OF QUALITY OF LIFE FOR THE  
SELF AND FOR SOCIETY AS A WHOLE. SOCIOECONOMIC IRRESPONSIBILITY IS A SYMPTOM  
OF THE SAME PSYCHOSOCIAL DISEASE WHICH RESULTS IN PATERNALISTIC OPPRESSION OF

This is life. . . . This is no make-believe world where you can go jumping into everything and it will be OK. You have to live up to your responsibilities and answer for your errors.

Herschel Walker

The movement for independent living has adopted many of the same money-saving arguments for deinstitutionalization used by other groups. The only problem is that many of these arguments are beginning to wear thin with representatives of the taxpaying public who have not witnessed any significant decrease in human service expenditures.

Gerben DeJong

The movement should not demand too many expensive programs; doing so could damage its credibility and reduce its effectiveness significantly. Neither the movement nor disabled individuals should rely too much on government and other outside funding, and expensive technical aids; such reliance fosters dependence rather than independence.

Gini Laurie, Editor  
Rehabilitation Gazette

INDIVIDUALS WITH DISABILITIES. In a society too often characterized by attitudes of self-centered, self-defeating escapism--in an inefficient, spendthrift society, the lives of disabled people are almost always among the first resources to be wasted. Cutting waste, cutting expenditures for paternalistic self-indulgence is our issue. Productivity, defined as that process which results in an efficient production, distribution and utilization of the material and psychological components of quality of life, is our issue.

We must, in order to achieve our goals, learn to live well on our fair share of society's resources, and to make our civic, employment, commercial, and personal activities maximally productive. Emphasis must be placed on what we can give, as well as what we insist on receiving. Our organizations, our advocacy, our personal lives must demonstrate the truth that status oriented paternalism is wasteful and that independent living is profitable. Productivity is potentially our best issue and -)ne of our most effective weapons. We must demand it; we must live it.

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The authors also recommend that independent living programs reserve their very modest resources for investment in activities which contribute maximally to the survival of a philosophically and administratively independent movement, such as advocacy, information and referral and, perhaps most important, the support and education of those who have the potential to become effective participants in society--individuals who would form the foundation of a stronger movement able to take advantage of the opportunities that certainly will come. In a society characterized by psychological and physical violence and deprivation, socioeconomic instability, and general inefficiency, it is absolutely vital that our leaders and members, both disabled and non-disabled,

The dignity of risk is what the movement for independent living is all about. Without the possibility of failure, the disabled person is said to lack true independence and the mark of one's humanity--the right to choose for good and evil.

Gerben DeJong

develop personal living skills which are far superior to the norm. Efficient management of such as time, budgets, investments, nutrition, health care, emotions, and family and social affairs is essential to successful living and effective advocacy leadership.

Given the vast numbers of disabled and other disadvantaged persons who need independent living training, this allocation of severely limited resources may involve some apparently cruel and certainly unfashionable decisions. However, no group or society known to the authors has ever prospered by depriving the strong to nurture the weak, or by depriving all its constituents in order to divide hopelessly limited resources equally. The first priority of any worthwhile entity is to survive.

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Many activists present the thesis that choosing popular issues which can easily be won is the key to the organization of a successful movement. Often there are implications--sometimes direct statements--that careful, profound philosophy, patience and great ideals are vaguely related, unrealized or negative to the accomplishment of movement goals. Projects and leaders unable to achieve visible success in short periods of time are said to be ineffective--even counter-productive. "Failures" and "losers" are to be avoided at all costs. "Winning is the name of the game." Interpreted, as they often are, in simplistic ways, these ideas can be terribly self-defeating reflections of the modern addiction to instant gratification and "success."

It is certainly true that winning and the atmosphere of winning are important components of successful organizing.<sup>26</sup> But winning can have

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<sup>26</sup>For all thirteen years of its existence the goal of our private independent living program has been expressed in one word: "WIN!" (WIN!: convert your dream of responsible independence into a lived reality.) We feel that the project has been successful.

The process of reconstruction is  
stained with tears and blood. But  
the height the great masters have  
climbed cannot otherwise be reached.

D. T. Suzuki

positive meaning only to the extent that it constitutes real progress toward the great ideals--toward improvement in the human condition. And experience would seem to indicate that significant, consistent progress can only occur through a process which involves difficult, undramatic, long-term foundation building--including "failures," "retreats," "frustrations," and "Martyrs"--and when action is based on practical, indepth understandings of reality, on careful philosophy.

All of the really great popular movement organizers of history<sup>27</sup> have been able to mold a winning combination of visible short-term success, purposeful compromises, retreats and "failures," and practical philosophical understanding. And none of those "greats" could have presided over the triumphs with which they are credited without the patient, usually unfashionable labors of the plodders and the "failures," who struggled for the cause before them. and laid the foundations fo- their "success." The fact is that the best, the most completely successful programs involve large measures of what our culture would often call procrastination, appeasement or failure. Life simply does not conform to most of our wishful TV scripts.

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We need not, then, be dismayed by current or future social, political and economic problems--or be ashamed to retreat when necessary. It will be evidence of our strength and a mark of our creativity and resourcefulness if independent living programs and advocacy groups can, in times of economic hardship for human rights efforts, reduce their staff, facilities and services to the barest minimum and still be effective in furthering the goals of the movement. If all outside funding ceases and an organization is reduced to

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<sup>27</sup>For example, the early Christians, the American revolutionaries, Gandhi, Mao Tse-tung, Martin Luther King.

For approximately six years (1968-74) of economic hardship and frigid relations with the social welfare establishment, our private independent living program existed on a bare bones, survival basis in a previously abandoned Japanese farm house. Accessible? There was no flush or Western style toilet, no central heat, no ramp, no motor vehicle and a one-kilometer mud road to the railroad station. Wheelchair users--including the head of the program--dragged themselves over the straw mat floors. In the winter we kept the frozen food under the sink, and the fresh vegetables in the disconnected refrigerator; horse meat was a luxury generally reserved for parties. We continued to deliver services and to promote our beliefs through small scale, but forceful publications and community relations activities. A few individuals--everyone who stayed with the program--became independent. Very independent. The project survived and, with increasing confidence, improved economic conditions and the development of the American independent living movement, prospered.

What is the Tao (path, way, or truth)?

Walk on!

Ummon



a single volunteer staff person, a manual typewriter, a used mimeograph machine, a hand distributed newsletter, and donations by the members--backed by a determined, sophisticated, self-reliant, morally credible leadership--it can survive with dignity, power, and, perhaps, increased independence. And, although we would be ill-advised to relax our efforts to achieve active participation in the movement by all disabled persons, there is no reason to apologize that our organizations do not have millions of card carrying members, or that our functions are not always attended by hundreds of people. We represent the world's most severely disadvantaged minority; their relative silence, immobility and lack of resources are direct results of the vicious oppression which we rightly protest.

WE STRUGGLE FOR THE FULFILLMENT OF THE GREAT, TIME-TESTED, UNIVERSALLY ACCEPTED HUMAN IDEALS, AND WE SHOULD PRESENT OURSELVES POSITIVELY AND FORCEFULLY IN THE BEST TRADITIONS OF THE REFORMIST ROLE. JUST AS GANDHI DRAMATIZED THE NOBILITY OF GOING TO JAIL FOR TRUTH, WE SHOULD WEAR OUR DIFFICULTIES AS BADGES OF HONOR. UNTIL HUMAN NATURE IS SUBSTANTIALLY IMPROVED, A MOVEMENT FOR SIGNIFICANT SOCIAL REFORM--ESPECIALLY ONE THAT REFERS TO ITSELF AS "INDEPENDENT" --HAD BETTER BE PREPARED TO TOUGH OUT SOME VALLEY FORGE WINTERS.

An American renewal is entirely possible. But it is not inevitable. It will not be accomplished by rhetoric, chest-thumping, self-hypnosis. It will take great and disciplined effort, and exact a considerable price. It will also require a virtue rare in America: patience. . . . The need for renewal ranges well beyond economics, politics, and defense; it encompasses ethics, morale, social and spiritual values. . . .we face a crisis of moral responsibility, . . .

Henry Grunwald  
Fortune, March 9, 1981

## Conclusion

The time has come to recognize the limitations of and to modify our present methods, and to refine the conceptual foundations of the independent living and disability rights movement and of our own personal existences. The time has come to mobilize all of our resources toward the achievement of our ultimate goal: development of the individual who makes a total, efficient, consciously focused effort to become maximally productive in terms of quality of life for the cause and effect unity which is self, society and natural universe--and who will be able to continue and increase this mature expression of independence when contact with the independent living program or the movement has been reduced or terminated.

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LET US MAKE NO MISTAKE ABOUT WHAT REACHING OUR GOAL WILL INVOLVE. WE ARE ATTEMPTING TO CHANGE THE FUNDAMENTAL OPERATIONAL VALUES OF AN ENTIRE CULTURE, TO ALTER THE VERY SHAPE OF HUMAN NATURE ITSELF. We are attempting to replace psychosocial patterns rooted in prehistory, and, perhaps even in the present biological constitution of human being. We are attempting to overcome entrenched personal habit and current popular and intellectual fashion. We are attempting to comprehend and to fulfill responsibilities which seem (to our present simplistic, baroque consciousness) at once vague to the point of meaninglessness and complex to the point of incomprehensibility.

Unless we are willing to accept the superficial success of most of today's fashionable political, religious and intellectual movements--the symbolic substitution of partial results and rituals for society-wide accomplishments, the placing of new labels on old concepts, and the transfer of power and prestige to a few new leaders and groups--if we seriously intend to establish

BUT WHAT CAN ONE LONE INDIVIDUAL, WHAT CAN "I"  
DO THAT WILL MAKE ANY DIFFERENCE? I CAN'T  
FIGHT THE WHOLE SOCIETY; I DON'T RUN THE  
GOVERNMENT.

THE FIRST ANSWER IS THAT I AM (THE BASIC UNIT  
OF) SOCIETY. I AM THE GOVERNMENT, I AM THE  
DIFFERENCE - THE ONLY DIFFERENCE. ONLY WHEN  
I CHANGE WILL SOCIETY AND THE GOVERNMENT CHANGE.

THE RESPONSIBILITY IS MINE.

maximal equality and quality of life opportunities for all disabled persons, we must attain levels of passion and patience, of sustained, self-controlled rationality, of individual initiative and responsibility, and of complementary unity which have never been reached by any large segment of society. History and current conditions would seem to indicate that this will be more than difficult. Certainly no final goals will be reached in our lifetimes--or probably during the lives of our children. Our success, even to accomplish a substantial, foundational beginning, would constitute a quantum leap in the pursuit of psychosocial change; it would be historic in a sense which gives new and larger meaning to the term.

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Is not this attempt to change basic human values an impractical, "utopian" venture? On the contrary, it is the currently fashionable approaches that are impractically utopian--the promise, the expectation of instant, storybook solutions based on the hypotheses that human beings are essentially rational, that problem-free, happy-ever-after states of consciousness and social situations are attainable, and that "society" can somehow provide the good life without responsible action by the individuals who are society. The authors propose no such panaceas. They simply advocate the acceptance by each individual of complete responsibility to face and do battle with self-defeating addictions, and to utilize currently available resources to effect that life quality productivity which is possible today. They advocate the type of (relatively unromantic) history making that occurs when one person purchases a bicycle instead of a station wagon or volunteers to clean the independent living center on a regular basis. These goals are indeed difficult to achieve, however they are utopian only if man is doomed to surrender unconditionally to his irrational characteristics.

Whatever the institutional mechanics of it, the real renovation of America must begin in Americans' minds. It must express itself in their civic morale, their sense of individual responsibility for themselves, for the communities and the nation around them. It is not enough to say that the Government has failed, that the System has failed. That accusation subtly absolves individual citizens of blame but also leaves them feeling like abjectly passive victims of immense conspiracies--bureaucracies, multinational corporations. No society can flourish, or even function, if its people do not feel responsible for it any more. . . . America will get better only when Americans are convinced that it is up to them to make it better.

Lance Morrow  
Time, February 23, 1981

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Nevertheless, history and current events discourage us; a multitude of fashionable escapes tempt us. Can we succeed? Is it worth the effort? Whatever the odds for total success--and they do not seem to encourage a great deal of optimism--there is only one sane answer: we must accept the challenge. Life offers no rational alternative to a policy of survival and maximized quality of consciousness. One centimeter of additional progress, one extra moment of life quality existence, in combination with the profound security of facing reality squarely, is far superior to the terrible cost--the frustration, the anxiety, the waste, the actual physical deprivation--of our present attempts to maintain illusions and to rely on miraculous cures.

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There are some encouraging factors. Our culture has developed technology, psychosocial methodology and philosophical concepts of great power. There is an increasing world-wide focus on humanity's vast failure to utilize these resources for the enhancement of life and a growing body of support for the development of solutions.

We who are termed disabled have secured social and official recognition for our basic rights and principles. We have recorded partial, but significant gains in areas such as health, education, employment, mobility and public acceptance. And we have produced a small, but potent group of remarkably creative and responsible individuals, whose existences are awakening centers of independent action and communication. Our constituency, probably the world's largest and most severely disadvantaged minority, cuts across every cultural, national, racial, ideological, economic, age and sex group. We

What an opportunity we have! Independent living was once a dream, and now it is becoming a reality. A better future for hundreds of thousands of people with disabilities is within our grasp. . . .

Our greatest handicaps are outdated social attitudes, lack of opportunities and physically inaccessible environments. Together we can change all that and can create the new future. I urge you to take the challenge; . . .

Edward V. Roberts



have a distinctive dilemma, the solution for which is so demanding and so personally and dramatically urgent, that we may be able to find the special motivation necessary to face reality more squarely, to introspect more severely, to probe more profoundly into the bases of the human problem, and to take more responsible, more decisive and more immediate action than many of our able-bodied brothers and sisters. We have a dynamic leadership of exceptional natural ability and a potential to develop the passion, the dedication, the self-discipline and the intellectual focus necessary to plan and execute the appropriate action. We have the advantage of an "adversary," a society,<sup>28</sup> which, if it does not precisely support the actual accomplishment (as opposed to the ritual endorsement) of equal quality of life opportunity, has gone firmly on record in recognition of our basic rights and aims. In order to maintain the illusions of superiority, democracy and righteous concern for the disadvantaged which are necessary to the maintenance of its fragile self-image, there is a good chance that our society will continue for some time to underrate us, to define us as a group of relatively impotent subservients who offer little real threat to the status quo. For all of its oppressive mechanisms, the authors do not believe that the establishment has any present defenses capable of completely rejecting the positive influences of a dedicated, unified, self-reliant, morally credible, philosophically and organizationally sophisticated disability rights movement.

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<sup>28</sup>More precisely defined, our adversary is, of course, not society, but that body of obsolete attitude-action patterns which exists in all of our lives and dominates our perceptions of and participation in society.

I appeal to you as a human being to human beings:  
remember your humanity, and forget the rest. If you  
can do so, the way lies open to a new Paradise; if  
you cannot, nothing lies before you but universal  
death.

Bertrand Russell

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It is a commonplace that humanity stands at a crossroad of unprecedented magnitude. We are faced with dangers resulting from ecological, technological and psychosocial mismanagement (and/or evolution) which threaten a new dark age of starvation, sickness, poverty, and technology powered barbarity, or even extinction of life on earth.

We are, on the other hand, challenged by an opportunity, an apparent potential, to begin to fulfill, even to exceed man's fondest utopian dream of a life characterized by harmony with the reality of human being and its ecology. We have an opportunity to assist in the opening of a vast new frontier for humanity: experimentation with hypotheses which offer a high probability of significant progress for all those who suffer serious failures of potential in the present inefficient systems. We have an opportunity to establish psychosocial structures which would transcend most of the major perceptions of difference that form the basis for conflict among today's leading political and ideological groups, to create a dynamic, productive, relatively unified successor to socialism and democratic capitalism, a substantial fulfillment of the passionately advocated but vaguely focused revolutions and reforms of the great religions, the democrats, the traditionalists, and the Marxists. We have an opportunity not only to take effective control of our own lives, but also to assist in the birth of a new phase of humanity: life quality science Man--Man grown out of a primitive childhood of tribalism, through the present turbulent, dangerous, disorienting adolescence, and into a mature effort to be responsible for life, to use the best modern conceptions of morality, philosophy and science to maximize quality of life for the self and for all. WE HAVE AN OPPORTUNITY TO HELP LAY THE FOUNDATION FOR AN ACCESSIBLE

What are we doing with life? That question  
overtakes a reluctant and fugitive humanity.

H. G. Wells

Men who are good by reason--i.e., men who,  
under the guidance of reason, seek what is  
useful to them--desire nothing for themselves  
which they do not also desire for the rest  
of mankind.

Benedict (Baruch) Spinoza

WORLD COMMUNITY IN WHICH THE AVAILABLE HUMAN AND MATERIAL RESOURCES WILL BE USED TO ELIMINATE WASTE, WANT, AND INJUSTICE, TO PREVENT AND TO BYPASS DISABILITY AND TO EFFECT THE FULL UTILIZATION OF EXISTING ABILITIES--IN WHICH EVERY INDIVIDUAL WILL BE EMPLOYED 24 HOURS EACH DAY IN THE COOPERATIVE PRODUCTION OF QUALITY OF LIFE.

The dangers and opportunities presented by today's world--in combination with a fission-like acceleration in the rate of psychosocial, technological, and ecological change--present responsibilities so overwhelming that most humans are shocked into numbness, or seek refuge in orgies of escapism (which simply lead to increased deprivation and conflict). With the quality of our lives, with the very existence of our children hanging in the balance, we must somehow gather the strength to overcome our addictions to self-destructive stereotypes. We--Republicans, Democrats, Socialists, Marxists, Moslems, Jews, Christians, Bud & tats, Hindus, blacks, browns, yellows, whites, persons with disabilities, individuals of every race, nation, religion, class and ideology must learn to resolve the relatively trivial conflicts over personality, style, group labels and ideological symbolism which divide us and to focus on those sacred, traditional values of life which are agreed upon by all rational people in all cultures. We must learn to speak each other's language, and to work together--to achieve that dynamic, productive unity which results when mature, independent individuals act in harmonious complementarity. We must unite for life.<sup>29</sup>

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<sup>29</sup>It is tempting to dismiss statements of this nature as meaningless, melodramatic rhetoric, as somehow unreal--or to feel that these are not the problems of our movement. However these dangers, opportunities, and choices are the inescapable responsibility of every human being. And they are just as real as the dead of Auschwitz, the miracle medicines, the poised nuclear warheads, the computers, the great dinosaurs and civilizations which no longer exist because they failed to meet the challenges of their time and the thousands of disabled people who perish every week for lack of the basic necessities of life.

History seems to indicate that attempts to ignore dangers and opportunities tend to guarantee the loss of the opportunities and to maximize the probability that the feared events will occur.

Perfection of means and confusion of goals seem--  
in my opinion--to characterize our age. If we  
desire sincerely and passionately the safety, the  
welfare and the free development of the talents  
of all men, we shall not be in want of the means  
to approach such a state. Even if only a small  
part of mankind strives for such goals, their  
superiority will prove itself in the long run.

Albert Einstein

Neither god nor devil can undo the victory of the  
man who has conquered himself.

The Dhammapada

In this time of historic choices we who have disabilities, we of the disability rights and independent living movement have unique opportunities to progress toward our own goals, and at the same time to lead, to provide examples of responsibility for life which would constitute an unprecedented fulfillment of personal potential and a magnificent contribution to human being.

Whatever others may decide to do, there is no possibility of "failure" for those of us who choose to act for life. The dedicated, total effort of a single individual to live the universal, life quality ideals is a monumental victory for the person and for humanity. The unified efforts of millions could become an irresistible moral magnet.

Let us, each one of us, act for life today!

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There is no road  
before me  
My footprints  
form a path  
behind me.

Kotaro Takamura