



Independent Living and Participation in Research: a critical analysis

*Gary Woodill, Ed.D.
Chief Learning Officer
Operitel Corporation*

Preface by:

*Vic Willi, M.S.W.
Executive Director
Centre for Independent Living in Toronto (CILT)*

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Preface

Everyone is an expert on disability. To be disabled is to live in a world full of able-bodied people willing to impart their knowledge about what is best for us, how we should think, live and sometimes die. It wouldn't be so bad if we were just talking about the well-intentioned nuisances we meet in public, but that is not the case. One need only think of our brothers and sisters who, because they have disabilities, are forced to live in institutions against their wills. Because in the past, government policy-makers convinced their political masters that vast amounts of money should be given to professionals and custodial staff to 'take care' of us. The policy-makers and politicians justified these decisions on a seemingly endless stream of academic research done by highly qualified - albeit able-bodied - researchers and experts.

Few of us have escaped researchers' scrutiny or their seemly pathological fixation on the limitations and negative aspects of our lives. We have been portrayed as sick, helpless and incompetent, incapable of living independently. We have few champions, but we do have a few.

CILT found one of theirs in the person of Gary Woodill. We commissioned Gary to write this book and the first thing he told us was that we would have to be involved in the process. This is called participatory research and it is the theme of this work. I believe we have here a bright and beautiful thing, a powerful tool for taking back control of our lives and the process by which we are defined.

The rest is up to us now. We have witnessed the debacle which ensues when social policy is based exclusively on the assumptions of misguided able-bodied professional experts. They said we would be better off in institutions where, as it turns out for quads, you die 10 times faster than if you were living free in the community. People with disabilities are the real experts. We are the ones who must define the policies and services we need to become empowered citizens with access to the benefits of our society.

Read this book, study the guidelines at the end of the book for deciding which research projects will empower us, and learn how to reject those that will oppress us. Apathy is toxic. We must help each other to gain independence and control. This book is a step in that direction. Thank you, Gary.

Vic Willi
Executive Director
Centre for Independent Living in Toronto (CILT)

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Introduction

As the number of Independent Living Centres increases across North America, they have become a subject of interest to researchers in rehabilitation, medicine, social work, education, and other professions with an historic interest in persons with a disability. Increasingly, academic researchers - faculty, graduate students and research consultants - are approaching Independent Living Centres, or individuals with a disability, with requests to participate in research involving Independent Living and disability. Independent Living Centre staff are for the most part disabled themselves, but often do not have the academic background to effectively respond to these requests in a rationale way. The purpose of this discussion paper is to assist in the task of assessing research proposals, by critically examining what is involved in the politics of disability research.

In order to situate scientific research on disability, a historical and critical perspective is used in the first chapter to review what problems have traditionally existed with academic research from the point of view of the subjects of that research - persons with a disability themselves. Any new research on disability must take into account the fact the old theories of disability are rapidly disappearing, and that new models and definitions of disability, this time formulated by persons with a disability, are taking their place. This new view of disability is discussed in Part 2, as it will influence all research on disability in the future. Similarly, there are changing ideas of what is meant by "Independent Living", and three different models of that concept are examined in Part 3. As if all this change was not enough, we are also living at a time when the ideas of science are also in flux, and this also has implications for new ideas on disability research. These implications for disability research are outlined in Part 4. Finally, Part 5 gives some concrete guidelines for assessing research proposals, using much of the theory which has been developed in previous chapters. A decision support template and a sample consent form follow as appendices.

PART ONE

Research on Disability: Critical Issues

For the past two hundred years or so, disability and persons with a disability have been one of the objects of study of social scientists (Stiker, 1982). The scientific study of persons with a disability has several roots, including developments in anatomy, neurology, and germ theory in medicine, the rise of statistics in sociology and psychology, and the demands of social insurance to discriminate between those who should receive benefits and those who should not.

Medicine is the oldest profession to scientifically study persons with a disability. In fact, when the first state welfare offices were opened in the 1530s in France, it was the "barber-surgeons" who were hired to examine those who were applying for welfare benefits, in order to determine who was really disabled, and who might be faking a disability.

The development of medical knowledge has a long history, but in the 17th and 18th centuries important changes which had an impact on persons with a disability included the discovery of the electrical nature of the brain, the invention of new technologies for examination such as the stethoscope, and the switch from the theory of "humors" in explaining disease to germ theory. In particular, germ theory gave the doctors immense power because unlike the previous theory which required the patient's cooperation to "balance the humors", germ theory had as its metaphor a war against invading germs; the doctor was the heroic soldier and the patient was the battleground. It was here that whatever small amount of power and control a patient had was lost to the "medical gaze" (Foucault, 1973), as this life and death struggle between germs and the doctor was waged. Patients who had their own opinions on what was happening inside their bodies were often seen as dangerous in this all out war.

The 18th and 19th centuries were also the time when social statistics were developed and used to formulate theories of human functioning. In the 1840s, the Belgian astronomer A. Quetelet first suggested the concept of "the average man". From the *average*, which for Quetelet was the place of human perfection, arose the idea of the norm and the "normal". Of course, those who fell outside the average range on either side of the middle became the "abnormal" or "pathological". This statistical notion of abnormality (also called "error"), came to be applied in medicine, sociology, and psychology.

Statistics were also used in the 19th and 20th centuries for drawing up mortality tables and making predictions concerning the prevalence of sickness and accidents for life insurance, workers compensation schemes, and social welfare benefits. In this context, disability came to be defined as "an inability to work", and compensation was paid on the basis of elaborate formulae which calculated the degree of impairment for various body organs (Stone, 1984).

The beginning of the twentieth century marked the rise of eugenics, a scientific approach to human reproduction which sought to have the "less fit" removed from the "human stock". Many studies of mentally handicapped persons and their families were carried out to "prove" the eugenics arguments, all supposedly based on "scientific methods". The results are well known - incarceration of hundreds of thousands and involuntary sterilizations in many countries including the United States and Canada, and ultimately the murder of many sick or disabled persons by the Nazi regime. As Robert J. Lifton has documented in his book *The Nazi Doctors*, the killing of persons who were disabled or sick was carried out before the mass killing of Jews. In a real sense, the murder of persons in hospitals in the name of science, and the lack of any outcry, was a form of practice for the Holocaust.

While much of the study of persons with a mental or physical disability has resulted in less drastic treatment than death, many persons with a disability have been confined, subjected to treatments without their consent, and abused with the tacit or explicit approval of professionals trained in scientific research.

Of course, many professionals have not acted like this, but many have "objectified" the person with a disability in the course of research or treatment. One of the reasons for this objectification is that both medicine and the social sciences borrowed much of their research methodology from 19th century physics and chemistry. The success of these "hard" sciences impressed the researchers in the new fields of psychology and sociology. In particular, science was seen as studying "objects" in a "value-free" manner, in order not to show any bias in the results of research studies. Applied to the social sciences, this became a set of ethics which included treating humans as discrete individual objects, using numbers to describe human behaviours, and maintaining as "objective" a stance as possible to the objects under scrutiny (usually referred to as "subjects").

The result of this type of research was to leave out the perspective of the subject in any consideration of the design, methods, or results of research. It can be argued that this paradigm of research methodology in medicine, psychology and sociology has been oppressive of disabled people, and does not fit with a philosophy of Independent Living, or considerations of a person's "quality of life". As one writer put it:

“The problem...is that medical people tend to see all difficulties solely from the perspective of proposed treatments for a 'patient', without recognising that the individual has to weigh up whether this treatment fits into the overall economy of their life. In the past especially, doctors have been too willing to suggest medical treatment and hospitalisation, even when this would not necessarily improve the quality of life for the person concerned. Indeed, questions about the quality of life have sometimes been portrayed as something of an intrusion upon the purely medical equation.” (Brisenden, 1986, p. 176, quoted in Oliver, 1990, p. 5)

In his book *The Politics of Disablement*, Michael Oliver (1990), a British sociologist who has a disability, lists three main problems with previous research which uses disabled people as subjects. These are:

1) most research questions given to disabled persons in questionnaire form "ultimately reduce the problems that disabled people face to their own inadequacies or functional limitations" (p.7);

2) most research with disabled persons as subjects "has failed to improve the quality of life for them, while doing no harm to the career prospects of the researchers" (p. 8-9); and,

3) "the theoretical underpinnings of much research on disability have usually been so divorced from the everyday experience of disabled people that they have felt victimised by professionals..." (p. 9).

Oliver concludes that "for these reasons more and more disabled people are refusing to participate in research over which they have no control and which they regard as likely to further their oppression" (p. 9). In a recent article, Michael Oliver (1992) calls for "changing the social relations of research production" (p. 101).

The social relations of research production provide the structure within which research is undertaken. These social relations are built upon a firm distinction between the researcher and the researched; upon the belief that it is the researchers who have specialist knowledge and skills; and that it is they who should decide what topics should be researched and be in control of the whole process of research production.

To leave these social relations of research production unchallenged is to leave the task of setting a research agenda for the 1990s in the hands of these experts. The very idea that small groups of 'experts' can get together and set a research agenda for disability is, again, fundamentally flawed. Such an idea is the product of a society which has a positivistic consciousness and a hierarchical social structure which accords experts an elite role. Agenda setting, whether it is in politics, policy-making or service provision, is part of a process of struggle and this is equally true of agenda setting in disability research (Oliver, 1992, p. 102).

What is needed, then, is a much better social theory of disability, and a set of research procedures which allows persons with a disability to have control over the process of research so that it is not used in a way which is oppressive. Instead, what is needed is an approach to research which contributes to and strengthens the goals of Independent Living. In order to do this, the concepts of disability, Independent Living, and research need to be carefully analyzed to see if it is possible for social research to be beneficial to persons with a disability.

PART TWO

Towards a New Social Theory of Disability

The type of research which one does is greatly influenced by one's position and perspective on the world. Researchers on disability bring with them a particular theory of disability which influences the kind of questions they ask, the kinds of phenomena they attend to, and the kind of conclusions they reach. Therefore, for supporters of the Independent Living movement, it is important to critically examine the range of theories which are operating today in the field of disability studies, and to propose changes in those theories which do not fit with an Independent Living philosophy.

Michael Oliver (1988) has identified four principal theories of how persons with a disability are portrayed in social science and social policy research in Western societies. The first is the *humanitarian account* where disability is seen as *personal tragedy* (or its converse, *personal heroism*). Because having a disability is seen as tragic, humanitarian perspectives on disability tend to focus on *helping* the person with a disability to *overcome* his or her individual situation. Those disabled people who are recognized as high achievers in society take on the cultural status of heroes; examples include Helen Keller, Terry Fox and Rick Hansen.

Another account of disability social policy is the metaphor of *social investment*. In this *functional* approach, persons with a disability are seen as "human capital", and investment in the welfare of disabled persons is based both on cost-benefit analysis and the need for social and political stability. Such an approach would argue that it is more economical to place persons with "special needs" in the community rather than in institutions, particularly when such people can be now controlled with drugs, therefore posing no threat to the general population.

A third account of disability social policy is based on several *conflict theories*. The *pluralistic* view of conflict theory sees disabled people as one more social group clamouring for scarce resources, and they must compete for funds with other groups in society. *Marxist* conflict theory reduces this struggle to conflict between classes - labour and capital, workers and bosses. Some theorists use Marx's notion of "surplus populations", brought into the labour force when needed, and discarded later, to explain the position of persons with a disability in our society.

Finally, a *social control* view of disability policy argues that groups which can be demanding need to be pacified and controlled through minimal benefits, legislation, forced exclusion and professional power. For example, legislation on benefits for those who are unable to work is structured so that only the bare necessities are given, in order to ensure that those who can work will continue to work rather than applying for welfare benefits. Thus both those unable to work and those able to work are kept in their "proper" places in society. These four understandings of the situation of persons with a disability

are accompanied by three different definitions of disability. In the *individualistic definition*, the person with the disability is seen as having a problem, and efforts are made to help the individual to cope with life. In the *social construction definition*, disability is seen to exist because it is defined as disability by other people. If categories of disability are not thought about or defined, then the problems of disabled people are seen to disappear. In the *social creation definition*, it is argued that society "disables people with impairments by the way it responds to those impairments" (Oliver, 1988, p. 17). For example, inaccessibility is seen as a result of how buildings are designed, and not from the inability of some people to walk. Other created barriers include systemic and attitudinal obstacles to acceptance.

Oliver, along with the leaders of many organizations of disabled people, seems to favour the third definition of disability, that society creates disability out of neglect in designing for the needs of those who are mentally or physically different from the majority of the population. An even more radical position is to see disability in its negative meanings as a fiction, and to view being mentally or physically different as a positive state of being, or as simply a matter of being *culturally distinct*. This view has been most recently articulated by members of the Deaf community, who sometimes argue that prevention programs are a form of *cultural genocide*, and that more deaf children need to be produced in order to keep a healthy Deaf culture. Similarly, Jean Vanier has argued that the world needs mentally handicapped persons in it in order to teach those who are not mentally handicapped about values of caring and generosity of spirit (Vanier, 1971).

How does one decide among all the above competing accounts of disability and social policy towards disabled persons? I would argue that each of the above positions is a partial view which contains some merit, but which is incomplete because it excludes points of view which also have some validity. A fuller account of disability is *complex* in that there are many different aspects which need to be described in order to gain a full picture of the life situation of someone who has a disability.

There is no *essential* disabled person. There are no essential qualities which would warrant a person being described as disabled. That is, saying that a person is disabled says nothing about the person that is clearly distinctive from a person who is not described as disabled. What we mean by this term is culturally and historically specific, and therefore relative. As well, the value placed on the person who is labeled disabled, the roles expected of that person, and the behaviours of others towards that person are also all culturally and historically relative. One Swedish philosopher, Lennart Nordenfelt (1992), has suggested that we cannot properly speak of disability with any real meaning unless it is in the form of a statement such as: *Person A is disabled given that he/she has vital goals X and is prevented from realizing these goals by circumstances Y.*

Having a disability, as defined in Western societies at the present time, applies mainly to *individuals* rather than groups defined by some other criteria. Groups of disabled persons are seen as groups of individuals *with* disabilities. One reason for this view is the recognition that having a disability is possible regardless of class, race, or gender. Thus there is a certain truth to the perception that disability is a personal issue, and given that

most disabilities involve a loss of some area of human capacities, it is not unreasonable to expect that most people would not want someone to have a disability if it can be prevented. However, this does not warrant a continuing view of someone who has a disability as having a life which is *tragic*. Paul Abberley (1987), another British sociologist who is disabled, has noted that we must hold two separate attitudes to disability at the same time. On the one hand we should try to prevent a person from becoming disabled if prevention is possible, and on the other hand, we must affirm and not devalue persons who already have a disability. And while having a disability is lived on an individual level, it is neither a personal tragedy, nor an *exclusively* personal matter.

As individuals, most of us do not exist in isolation; rather, most of us live *in relation to others*, and to an entity we term society. As well, we live in *multiple subject positions* (Smith, 1988) in society; we do not just have one identity. We act as individuals with *agency*, but almost always with regards to others' views of us, and with regards to our perception of our *social status* or position in the society. Thus the attitudes of others do make a difference in how one is seen, labeled and treated. To that extent, the social constructionists are correct. But this too is an incomplete account in that it does not recognize that many (but importantly not all) disabilities are either caused by technology (such as weapons, airplanes or cars), are the result of advances in medicine which allow many severely disabled persons to live who would have died in previous times, or are seen to be problematic because of correctable barriers to accessibility in a society.

The social creationist view is also limited to the extent that it doesn't recognize its cultural relativity. Not all human capacities are restorable through technology or through removal of barriers. As well, much of the social creationist argument refers to the *designed environment*. In societies without advanced technology, where the natural environment is more prominent in daily life, it would not be reasonable to see all problems of disability as created by the society. While it is reasonable to suggest that steps *create* a disability for persons in a wheelchair, it is not reasonable to suggest that the lack of ability to move through the jungle in a wheelchair is a problem created by a society which lives in the jungle. Therefore, when humans create or design their environment they should take the needs of disabled persons into account. At the same time, all problems associated with having a disability cannot be reduced to a situation created by the society. Perhaps the attraction of the social creationist position is that it counters the common tendency in society to "blame the victim" with a reversal. Attractive as that may be, the limitations of this account need to be acknowledged.

However, the social creationist position is most useful in confronting us with the idea that the exclusion or inclusion of persons with a disability in the life of a society is primarily a social act. For example, by studying bones found in graves, archaeologists have confirmed that a number of "pre-historic" societies had members with identifiable disabilities, who were, at the same time, buried with all the ritual objects found in other graves of the same society (Scheerenberger, 1983). This indicates that even if the natural environment posed some natural barriers to movement for disabled members of these societies, they nevertheless lived in a condition of acceptance and dignity in their community.

A new social theory of disability must recognize all of the above. It must explain how the category of disability occurs, how it is maintained, and how it may be modified, while recognizing that persons exist as *individuals-in-relation-to-society*. We begin with an analysis of how some human differences are recognized, and then turned into the category we term disability.

The Creation of the Category of Disability

Human differences are produced in many ways. Sexual reproduction functions to ensure that offspring are different than their parents, through the mixing of genetic codes to produce a child not identical to either parent, through the random matching of recessive genes to develop characteristics which have been dormant in the family line for generations, and through genetic mutations. Yet it is similarities which are remarked on in the new-born - for example, how much the child looks like one parent or the other. The human infant is recognized as fully human to the extent that it is in the likeness of other human infants, i.e., its characteristics fall within the culturally accepted norms for the species, and for the child's particular gender. The concept of species and species boundaries are important to the definition of humanness, and if a child varies too greatly from the norms of the species, then he or she may not be recognized as human. Indeed, the first requirement of life is the recognition by some adult humans, usually the parents, that the child belongs to the human race and will receive care.

A second way differences are produced is through physical means such as accidents, abuse, war or cosmetic surgery. The injury of a child in the prenatal/perinatal/postnatal environment is not part of biological reproduction, but is due to the intervention of a destructive force. Drugs, alcohol, tobacco, malnutrition and physical injuries, along with the genetic factors mentioned above may all contribute to produce differences which are then interpreted as impairments. Such destructive influences are a major focus of prevention programs. Accidents which leave permanent injury, a feature of industrial societies, are another source of disabilities. War injuries also contribute to the production of impairments, although generally the war-injured have been honoured and treated better than those who were born with a disability. Many of the social benefits and provision for disabled people, for example, occurred first as a provision for the war wounded, beginning with pensions in ancient Greece (Stiker, 1982), up to the provision of social insurance benefits for war veterans in our time (Stone, 1984).

The Social Construction of Difference

While biological and physical factors can produce physical differences in humans, it is the recognition and perpetuation of meanings of specific differences that allows us to speak of the social production and reproduction of differences. As Schur (1971) states that " 'Deviance' is not a property *inherent* in certain forms of behaviour, it is a property conferred upon these forms by the audiences who directly or indirectly witness them. Sociologically, then, the critical variable is the social audience since it is the audience

which eventually decides whether or not any given action or actions will become a visible case of deviation" (p. 43).

Even if a person has a specific impairment, it is a social act to be recognized by oneself or others as a "disabled person". Many people who are eligible for disability benefits under various social insurance plans simply refuse to register themselves as disabled. This shows how disability and need are relative terms: the effects of a particular physical, mental or social condition cannot be defined in the abstract, but can be defined only in relation to individual expectations, individual attributes, reactions of others and one's self-concept. Thus, a lawyer who is blind may have more in common with a lawyer who can see than with a newsagent who is blind, but in the perceptions of the general public the attribute of blindness may be an overwhelming classifying factor. The possibility of stigma attached to the use of an aid is also culturally relative - glasses are accepted, and may even be desired to project maturity, while hearing aids and wheelchairs may lead to stigmatization.

The beginning of a disability category is the recognition of an important difference by those who have the power to define the situation, followed by a labelling of the recognized difference as a "disability". For example, while it might seem obvious that a person who is blind is disabled, this "fact" rests on several social constructions. First, there is the recognition of difference in terms of a sensory ability, but contrary to common belief, most "legally" blind people have some sight. Those termed blind have passed an arbitrarily set threshold of the measurement of visual functioning. This threshold has little to do with a person's ability to function in the world, which is dependent on the person's adaptation to his or her loss of sight, and to the demands of the specific situation on the person who has been defined as blind. Second, the perception that blindness results in a different experience of the world, and that blind people are "abnormal" or have "special needs" is a majority point of view which is based on the rarity of finding blind people in one's daily life, and being in a world which has not been specifically designed for blind people.

The philosopher Wittgenstein (1980) once asked, "What would a society all of deaf people look like?" One answer to Wittgenstein's question is found in Groce's (1985) book *Everyone Here Spoke Sign Language*, which documents a 250 year period when hereditary deafness was very common in Martha's Vineyard in the United States. Almost every family had at least one deaf person, and everyone interacted on a daily basis with many deaf people. Rather than marginalization and stigma, the presence of a large number of deaf people resulted in widespread bilingualism. A vernacular sign language developed and became used throughout the island, and in the nineteenth and early twentieth century almost everyone in the community, hearing and deaf, used sign language in all social and personal contexts. Because sign was learned early in life it was commonly adopted by hearing people, and sometimes even preferred in such situations as being secretive in front of strangers or communicating to other backyards or to another fishing boat. Sign language was so common that the elderly men and women who were Groce's principal sources had difficulty in remembering who was deaf and who was not deaf in their community.

Several writers have argued that the way a disabled person is perceived, and therefore, after a period of "adjustment" or training, is forced to act, is a social construction.

When those who have been screened into blindness agencies enter them, they may not be able to see at all or they may have serious difficulties with their vision. When they have been rehabilitated, they are all blind men. They have learned the attitudes and behaviour patterns that professional blindness workers believe people should have. For the intensive face-to-face relationships between blindness workers and clients that make up the rehabilitation process, the blind person is rewarded for adopting a view of himself that is consistent with his rehabilitators' view of him and is punished for clinging to other self- conceptions. He is told that he is "insightful" when he comes to describe his problems and his personality as his rehabilitators view them, and he is said to be "blocking" or resisting when he does not. Indeed, passage through the blindness system is determined in part by his willingness to adopt the `experts' views about self. (Scott, 1969)

Special education and rehabilitation derive their legitimacy as institutional forms from both the need for exclusion of deviance and from the religious ethic of helping those in need. Exclusion is always "masked with love" (McKnight, 1983) because open admission of administered inequality would contradict the public ethics of the administrator. "For their own good" has been a key phrase when people are being institutionalized as well as deinstitutionalized. In both cases the existence of a professional group and a client group is maintained. In the case of deinstitutionalization, modern drugs are sometimes able to create an institution without walls.

The institutional arrangements for persons with disabilities have often been accompanied by humanistic sentiments. The Warnock Report in Great Britain has been characterized as "benevolent humanitarianism", which "stressing the `charitable' and the intervention of the government to `make good' deficiencies, creates the impression of spontaneous development from purely humanitarian motives" (Tomlinson, 1982, p. 27). But "despite the benevolent rhetoric, special needs is a mystifying concept directing attention away from the needs that are actually being served by the expansion of special education" (Ibid, p. 73). From a general confinement of all the "unwanted" elements of the society there has been an increasing differentiation of categories with their corresponding service systems. Along with this has been a growth in the number of different professions involved with those seen to be "in need". Those who have the slightest differences from the norm are in danger of receiving diagnostic labels and being placed in professionally supervised special programs. The result has been a proliferation of professional discourses, training programs, and legislation - the development of an economy of professional "care".

The large custodial institutions often confined people from one or two years of age until death; deinstitutionalization has resulted in the service system for disabled children

moving in two directions - from school age programs to adult programs and to preschool, infant and perinatal/prenatal programs. A general philosophy of "the earlier the better" has prevailed in regard to the timing of the initial intervention. The implication of the trend to earlier intervention, however, may be that a younger child is more likely to be vulnerable to professional definition and control and less able to resist the induction into the 'moral career'(Goffman, 1961) of disability.

These trends reflect the changing powers of various professional groups to define and control the situation of the "deviant" person in society. The role of doctors was extremely important in policy-making in the nineteenth and early twentieth centuries because of doctors' reputation for "high moral character and discerning judgment...a person whose experience with human failings and weaknesses bestowed on him the kind of wisdom inaccessible to other professionals" (Simmons, 1982, p. 177). With the rising prestige of science, other groups could also register a claim to legitimacy in the treatment of persons with a disability. Further, as medicine shifted more towards a scientific base and away from moral prestige, doctors tended to confine themselves to those they could "cure", leaving others to work with non-medical problems. These shifts in power were reflected in changing concepts and vocabulary about the disabled. As educators became more prominent, words like "educable" and "trainable" replaced "idiot", "imbecile", and "moron". As psychologists gained influence, terminology of assessment, behaviour modification and therapy entered the field. Like the doctors, the new professionals invoked the power of science to justify their interventions into the lives of disabled people. The "clinical method" (also known as the "medical model") became the way of operating which ensured the maximum scientific respectability and the least resistance, and research became a powerful in the legitimation of the professional perspective on disability.

One of the results of professional social control of persons with a disability has been the relative silence of this group in explaining their own lives to others. As well, professional control leads to dependence, a state which has often been reinforced by the use of scientific research. Finally, as objects of study, disabled persons have sometimes been subjected to *dehumanizing treatment* in the name of science. But scientific methods have come under increasing scrutiny over the past twenty years, so that there are now approaches to research which promote subject input and control, and which are used for *emancipatory goals*. Given that Independent Living can be seen as a form of emancipation, these forms of research hold out the promise that research methods with persons who have a disability can be compatible with the goals of Independent Living.

PART 3

Models of Independent Living

The phrase "Independent Living" has been part of social service discourse since the end of World War II. Most recently, it has been used by disabled persons to describe a movement towards self-help and control of services which they receive (in this document this sense of independent living is capitalized). However, because of its long history in the professional literature, as well as its use by recipients of professional services, there are several meanings to the term in common use. These will be analyzed below.

The Professional View of Independent Living

The term "independent living" has a fairly long history in the field of human services. In the 1950s and 1960s, the term could be found in the titles of many textbooks in home economics. Here "independent living" referred to learning life skills necessary for living on your own. As the field of gerontology developed, the term independent living was used to refer to staying in one's own home, thus avoiding institutionalisation (e.g., Rosel, 1983). Owning your own apartment, even when it is a building designed for elderly people only (sometimes called congregate housing) is also termed independent living (Boles, 1983). In the gerontology literature, "independence" is opposed to "receiving help from others" (Mertens and Wimmers, 1987); elderly persons attending an adult day care centre would not be seen as independent (Harder, Gornick and Burt, 1986). Independent living may also be seen as one end of a continuum of services for older persons, or as Alperin and Richie describe it, there is a "full continuum of care - ranging from independent living in separate residential units to skilled nursing care" (p. 125).

This idea that independent living is at one end of a continuum of professionally supervised services is present in service systems for other client groups. For example, Shern and his colleagues (1986) describe a continuum of residential services for "the chronically mentally ill" where "inpatient" is at one end and "independent living" is at the other end, with four other residential choices in between.

A large number of studies (Anderson and Simonitch, 1981; Mauzerall, 1983; Baker, 1982; Ryan, McFadden, Rice and Warren, 1988; Mech and Leonard, 1988), use the term independent living as the opposite of forced supervision. For example, transition from foster care, institutional care, or living at home of parents to unsupervised living in the community are all termed independent living. Furrh (1983) even refers to "forced or selected independent living". Cook (1988) refers to "independent-living services for foster adolescents" which are defined as "programs and services provided by public and private agencies to prepare and support adolescents in their transition from supervised foster care placements to self-sufficient independent living". Some family and children services department of state and local governments in the United States operate "independent-living units" for youths leaving foster care (North, Mallabar and

Desrochers, 1988). Kroner (1988) describes independent living programs in this context as follows:

...What constitutes an independent-living program varies considerably. These services can range from a group home's weekly classes on self-sufficiency skills to clients living in their own apartment with occasional supervision and financial support. Some community agencies have a complete system of steps or gradations through which a youth can progress, with formalized training at each step. At this point most agencies have developed only one or two components of all the possible options. For the purpose of this article, independent-living services can be described as any effort, formal or informal, with the expressed purpose of preparing youths in out-of-home care for self-sufficient living. (p. 549)

Meston (1988) lists the following components of "phased" independent-living programs in Canada for adolescents leaving foster care: Training Unit/Preparation Unit, Supported Apartment Living, Apartment Living, Room and Board, and Extended Care. These various forms of independent living programs in the child welfare system may be accompanied by a "Independent-Living Program Information System", a case load tracking system for professionals in the child and youth welfare system (Tatara, Casey, Nazar, Richmond, Diethorn, and Chapmond, 1988).

In summary, the meaning of independent living in much of the professional literature concerning non-disabled groups is the absence of professional supervision and assistance. When it comes to persons with a disability, however, the meaning of independent living changes somewhat:

For many vocational rehabilitation professionals, IL services are for those for whom a vocational goal is thought to be impossible. Independent Living is seen as an alternative to the vocational goal - thus, the term "Independent Living rehabilitation" as distinct from "vocational rehabilitation." IL rehabilitation refers to those medical and social services that enable a disabled person to live in the community short of being gainfully employed. From this perspective, independent living and rehabilitation are seen as competing policy goals. (DeJong, 1979, p. 438)

As we shall see, this is a very different meaning from the concept of Independent Living as used by the grass-roots "consumer" movement founded and directed by persons with a disability.

The Market Economy View of Independent Living

Gerben DeJong (1979) wrote a seminal article on Independent Living which outlined its meaning for both professionals and disabled persons in the "Independent Living movement". The Independent Living movement seems to have started in 1962, when four "severely disabled students" at the University of Illinois were "transferred from a campus

isolated nursing home to a modified home closer to campus" (p. 437). In 1972 the Berkeley Center for Independent Living was incorporated as a *self-help group*, with the management of the center under the control of persons who were themselves disabled. The Berkeley center included the following services:

- peer counselling
 - advocacy services
 - van transportation
 - training in Independent Living skills
 - attendant care referral
 - health maintenance
 - housing referral
 - wheelchair repairs
- (DeJong, 1979)

When the Boston Center for Independent Living opened in 1974, it had a similar range of services, but added transitional housing. Other centres followed in the United States, each with its own blend of services and features. Unlike the Berkeley Center for Independent Living, many offered residential programs. The Independent Living movement spread to Canada in 1980 when DeJong spoke about the American movement at the Coalition of Provincial Organizations of the Handicapped (COPOH) Conference in Vancouver, B.C.

As DeJong noted in his 1979 article, "vocational rehabilitation professionals...have a different conception of Independent Living than do their consumer counterparts in the IL movement" (p. 438). The leaders of the Independent Living movement had adopted the model of consumerism as a metaphor for how they saw disabled persons relationships with professionals. As a consumer, the disabled person would, in theory, have the right to choose his or her services, service providers, and reject those providers who did not give good service. This model "asserts that because disabled persons are the best judges of their own interests, they should have the larger voice in determining what services are provided in the disability services market" (DeJong, 1979, p. 439). As a consequence of this choice of image, the term "disabled consumers" has entered the mainstream of professional vocabulary within the past five years.

There were other features of the Independent Living movement as outlined by DeJong, in addition to the consumer metaphor. These included an appeal to civil rights, a movement towards self-help, demedicalization/self-care, deinstitutionalization/mainstreaming/normalization, and a critique of the whole rehabilitation "paradigm", including a critique of disability research.

The view of Independent Living outlined as by DeJong has been strongly criticized in an article by Gareth Williams (1983). Briefly, his criticisms are as follows:

- in its "core constituency" the movement is biased towards young disabled adults, probably because it originated on university campuses

- the movement has a "basic commitment to the American capitalist system with its free-market pluralist ideology". This idea is based on the notion of a market of services in place of state-controlled monopolies of welfare services. But, as Williams notes, the many state run services grew up precisely because capitalism didn't provide for the most disadvantaged groups in society.

- the basic analysis of the problem is that disabled persons are constrained by "bureaucratic inertia and professional dominance" and that "the overriding goal is that people with disabilities should reclaim their own lives through reasserting their autonomy in opposition to state-controlled monopolies". Given this view, the leaders of the IL movement sees the best way of achieving their goals is by "the rational and competitive pursuit of personal interests in the political and economic market place". According to DeJong, "disabled persons...subscribe to the system's most cherished values and assumptions. they still want to become part of the system" (quoted by Williams, 1983, p. 1004)

- the market model of services and individual distributive justice avoids the issue of power except in the instance of individual exchange. We are all aware that many of the high-prestige service professions are well organized and wealthy. A single consumer shopping for services is unlikely to change this fact.

DeJong himself admits to dangers in the consumer approach to Independent Living, dangers to which the movement "must be on guard". These dangers include "tendencies to ignore the economic basis of political power, to conserve existing power relations, and to encourage a situation where one group will simply outbid and out-bargain other worthy groups in the skilled pursuit of scarce resources in the marketplace" (cited by Williams, 1983, p. 1004).

One concrete area in which DeJong sees a market economy flourishing is in the employment of attendants, perhaps because this group, unlike high-prestige professionals has little power. "...the attendant care market is largely deregulated. The disabled consumer is sovereign. The role of government is mainly that of financial intermediary." (DeJong, quoted in Williams, 1983, p. 1005) But attendants are human beings who will see a danger in being treated as objects by people who think of themselves as "sovereign" over them, and will organize against this.

This is a complex and sensitive area for discussion, and one which needs further research and thought. Attendants who work for agencies may see themselves as exploited by their management rather than by the persons with a disability for whom they work. The relationship between an attendant and a physically disabled person is often one of two-way dependency - with one person needing a job and the other needing services.

As Sandra Carpenter (1991) has already described, attendants are becoming unionized, and what might have evolved as a mutually beneficial relationship has in some cases deteriorated into a struggle among the desires of a group of disabled consumers,

management, and the fears and desires of a potentially exploitable group of workers. One suggested solution is the negotiation of one-on-one contracts with a third party mediator helping out, and direct funding to disabled consumers in order to give them more control over their own lives. Clearly this is an area in which simple consumerism fails to address a set of complex issues.

The Community Model of Independent Living

Both the professional view and the market view of Independent Living suffer from and excessive commitment to a philosophy of "*possessive individualism*," with little reference to a *sense of community of meaningful relationships*. In the professional model, the individual is seen as the *object to be serviced* - to be filled with skills and knowledge, before being sent out into the world, while in the market model, it is the individual as *possessor of material goods and control of services*.

Most of us, however, do not live without contact and relationships with others, while at the same time we all have some freedom to define our uniqueness. Individualism is only a partial view of human possibilities; it ignores the construction of meaning with other human beings. The creation of the *sense of community* (Sarason, 1974), does not come about by simply being placed in a certain geographical environment. Rather, it is built up through actions which recognize our interdependence, and our *solidarity* with each other.

All persons, whether disabled or not, have many things in common. We all use professional services to some degree, we all learn to do some things for ourselves. We all choose some aspects of our existence, we all have many things which are beyond our control. We all are capable of being in relationships with others - these others may be similar to us or different, but what counts is the connection. As the work of David Goode (1984) has shown, a researcher with a Ph.D. can develop a meaningful two-way communicative relationship with a deaf-blind adolescent who uses no formal language system.

John McKnight (1987) has noted that our mental map of the world of social policy usually includes two things - institutions and individuals. In business oriented North America at least, human service institutions are seen to produce service commodities, for which all of us are potential "consumers". Social policy makers who design medical service systems often refer to "health consumers". Mental health systems require "mental health consumers", school students are now "education consumers". Even professional staff can be called "consumers of management services".

This view of the world is problematic for several reasons. First, it doesn't work as smoothly as the policy planners would like. Many people, including criminals, school dropouts, and the homeless, refuse to play the role of a good consumer. Second, the costs for providing organized services for everyone is escalating, and financial constraints limit the application of the model. Third, the institutional services often produce a set of problems which creates a need for a new set of services, ensuring that the professional system grows.

For example, we now understand that our "correctional systems" consistently train people in crime. Studies demonstrate that a substantial number of people, while in hospitals, become sick or injured with maladies worse than those for which they were admitted. In many of our big city schools we see children whose relative achievement levels fall further behind each year. Thus, we have come to recognize the possibility that we can create crime-making corrections systems, sickness-making health systems, and stupid-making schools based upon a social model that conceives of society as a place bounded by institutions and individuals. (McKnight, 1987, p. 56)

What is missing in social policy, says McKnight, is the dimension of community. This dimension is also missing from both the professional and the market economy views of Independent Living.

A community model of Independent Living involves partnerships and relationships with other human beings rather than just service contracts. Relationships would be reciprocal and based on a equality of human status. Fallibility, uniqueness, and difference are accepted and seen part of being a person. Individuals are not isolated, but have a network of relationships, at various degrees of intimacy, based on common interests and shared experiences. Choice, control and individual achievement are balanced by acceptance, receiving, and community service by each member of the community.

What is needed is not to lose the gains made by the Independent Living movement to date, but to add on the dimension of community. This has started with such initiatives as the formation of "support circles", and the organization of social events and community meetings by Independent Living Centres. These beginnings need to be nurtured and grow, and are part of the vision of the founders of the Independent Living movement in Canada. As Sandra Carpenter, one of the founders of the Centre for Independent Living in Toronto described her vision in 1988:

The Independent Living movement represents a dream or a vision of consumer control and choice within the community. Rather than focusing on limitations and dependency on professional interventions, the emphasis is on quality of life and involvement in the community....Independent Living assumes that individuals will become empowered in society. (Carpenter, 1988, p. 2,4)

A community model of Independent Living recognizes that the psychological sense of community is often born in group struggle and striving for change. If disability is a social construction/creation, then it can also be socially redefined and the environment which creates disability can be modified. However, social change is rarely accomplished without some degree of opposition and resistance from those who are in power or from those who benefit by the maintenance of the "status quo". Those who work for change *together* will also develop a sense of community.

In her description of Independent Living, Sandra Carpenter states that "access to information, and knowledge of how best to use it is the key to empowerment" (1988, p. 4). The question to be asked, then, is what is the role of research in the movement towards Independent Living for persons with a disability? Are there types of research strategies which are more helpful than others? Are there types of research which are counter-productive to a community based Independent Living philosophy? It is to these questions that we turn to next.

PART 4

Methodologies for Disability Research

Until recently, most psychological, sociological, and medical research using disabled persons as subjects was based on a particular approach to research known as *positivism* or *empiricism*. This approach essentially held that the subject was a neutral object to be studied by a "value-free" scientist, using measurements which could be expressed in numerical terms. Positivistic research was developed in the social sciences in the 19th century by Auguste Comte, the French founder of sociology, and by a number of the pioneers in psychology, especially Francis Galton, James Cattell, and Karl Pearson (Danziger, 1990).

However, this dominant view of social science is changing, and it is this change which opens up the possibility for new approaches to research with disabled persons which are more compatible with the goals of Independent Living as defined by disabled persons themselves.

From Positivism to Pluralism in Research Methodologies

As Walker (1929) and Hacking (1990) have shown, statistics developed both as a form of decision theory and as a way of predicting the outcome of stable long run frequencies. Early applications of statistics included the distribution of gender at birth, the credibility of court testimony, the projection of population growth and economic indicators, the registration of land, projections of "man power" for military purposes, prediction of observational "error" in astronomy, and the outcome of various gambling games. In the early nineteenth century, Quetelet in Belgium originated the concept of "the average man" and "developed the conception of statistics as a general method of research applicable to any science of observation" (Walker, 1929:41).

It was Francis Galton, in *Hereditary Genius*, who claimed to be the first to introduce a "law of deviation from the average" into discussions of human beings. As well, Galton introduced the notion of grades in this book. "Galton placed the ablest men in each million in the highest grade, and the most stupid in the lowest grade, and then divided the remaining 999,998 into 14 classes, the average ability of each being separated from that of its neighbours by *equal grades*, thus forming a table concerning which he said 'the table may be applied to special just as truly to general ability...'" (Walker, 1929:87).

It is beyond the scope of this report to provide a detailed history and critique of the experimental/statistical method in the social sciences. Danziger (1990) has just completed such a study for the field of psychology, and he shows how a variety of techniques in nineteenth century psychology gave way to the supremacy of "group aggregate data" as the principal source of psychological knowledge.

Several writers have pointed out the ideological content of statistical techniques, especially its early connection to eugenics theory through Galton and Pearson. "Galton produced a vast range of quantitative studies on subjects ranging from fingerprinting to 'Statistical Inquiries into the Efficacy of Prayer'...Galton even confessed in an autobiographical passage to the habit of secretly counting and categorizing the women he passed in the street" (McLaren, 1990:14-15). MacKenzie (1978) contends that the choice of Pearson's r as the measurement of correlation (over competing statistics for correlation) was related its ability to support Pearson's strongly held views on eugenics.

Finally, as a decision theory, the test of significance in statistics has come under attack as being "insignificant". In his book *On Method*, Bakan (1969) tries to "show that the test of significance does not provide the information concerning psychological phenomena characteristically attributed to it; and that, furthermore, a great deal of mischief has been associated with its use" (p. 1-2). Atkins and Jarrett (1979) conclude that "there are no grounds for assuming that significance tests can serve as guarantors of the validity of research results, or that they can automatically sift out underlying laws of society buried in statistical data" (p. 105).

More recently the dominant model of research in the social sciences has come into question through new critiques of "the scientific method" in the philosophy, history and sociology of science. Recent writing in the history and sociology of scientific knowledge has challenged the traditional view of how scientific studies are conducted, and how the results of science are "replicated" and passed on to successive generations of scientists.

In the traditional *realist* view, scientists investigate a concrete reality by using theories to develop hypotheses, by testing their hypotheses through observation and experimentation, and by revising their theories based on their results/new knowledge. Some researchers contend that they only use pure observation to develop a set of "facts" concerning the phenomena under study. New knowledge is the result of "discovery" rather than "invention", and "progress" is the slow accumulation of knowledge in a particular field.

The new *relativist* view is that "science itself is an eminently social accomplishment. Rather than science standing independent of the social world by virtue of the methods it employs, studies have shown that those very methods, on a practical day-to-day level, are whole-heartedly social" (Doran, 1989:515). The production and reproduction of scientific knowledge is seen as framed in a surround of historical and cultural locations, social interests (Barnes and MacKenzie, 1979; Habermas, 1974), and an accumulated "story" which feeds and informs the methods and interpretation of "empirical" data-gathering. As Hazelrigg (1989) puts it, the world is "made" rather than "found". In its most radical form, this new view of science is self-reflexive; i.e., it can be turned back on itself to question its own social interests and cultural/historical position.

On the level of the production of scientific knowledge itself, knowledge has been shown to be highly influenced by preconceived philosophical/theological ideas, influenced by human desire for power and recognition, moved in certain directions according to the

political forces of the day, and born/made in the midst of intense social interaction and debate, attacks and support. It is not necessarily (or perhaps even usually) a rational process based on the careful collection and examination of evidence, but the application of preconceived positions and theories, using whatever means are available to find support for one's position.

These criticisms are echoed by those who support *qualitative* as opposed to *quantitative* research in the social sciences. As well, those who support a radical approach to inquiry called *participatory research* (PR) go even further in their criticisms of the traditional models of research in the social sciences.

Supporters of participatory research raise the following five criticisms of the traditional positivist paradigm in the social sciences:

1. The purpose of science is not only knowledge, but also the improvement of the quality of life. Established social research has been useful only to the powerful who can pay for and use it. It rarely results in benefits for the common people.
2. In prevailing practice, research topics are chosen either by policy makers and funding agencies in accordance with their interests or by researchers influenced by motivations of professional prestige. That is why most research turns out to be irrelevant to everyday life.
3. Social facts differ sharply from natural facts in two aspects: social facts are less determinate because they are affected by human intentions, and they are necessarily altered by the researcher who approaches them. (This happens in the natural sciences too, but to a far lesser extent.)
4. Neutral research of social facts is impossible. Knowledge is inevitably influenced by the prejudices, values, interests, and personal limitations of researchers. The effort to be objective, to establish a distance from social reality, often leads to overlooking essential characteristics.
5. Control of research by professionals has produced a monopoly on knowledge. Social knowledge, by its very nature, should be owned and used by ordinary people. (Latapí, 1988, p. 314)

Many of the above criticisms are similar to those by Michael Oliver, presented earlier, concerning the lack of relevancy of disability research for persons with a disability. Clearly a new approach is needed, an approach where knowledge is produced that "deepens and extends people's insights, enriches their understandings, extends their skills, and opens their eyes to new perspectives. Such knowledge could further their interests and alter their lives individually and collectively" (Rosenwald, 1988, p. 13).

In *Knowledge and Human Interests*, Jurgen Habermas (1984) outlines the "human interests" in various forms of social science research. In positivistic approaches, the interest is social control of others, in hermeneutic research (such as phenomenology) the primary interest is understanding the perspectives of others, while in critical theory research the principal interest is the emancipation of others and oneself from oppression.

Research methods can be placed on a continuum from the most controlling positivistic research to the most liberating participatory research, depending on the amount of control of the subjects over the research process. These relationships are depicted in Figure 1.

Figure 1 - Relationships among type of research, control and interests

| | | | |
|------------------|----------------------------------|-----------------|----------------------------|
| TYPE OF RESEARCH | Positivistic Research | Action Research | Participatory Research |
| TYPE OF CONTROL | Control <i>of</i> Subjects | Joint Control | Control <i>by</i> Subjects |
| RESULTS USED BY | Groups with Power, Professionals | Shared Use | Disadvantaged Groups |

As a social movement, the Independent Living movement as led and defined by disabled persons has an ethic of emancipation or liberation of persons who are under the control of institutional or professional structures. Given that, it would seem that the most appropriate forms of research to take place with the participation and approval of Independent Living Centres would be those which have a critical and emancipatory perspective, and which gave disabled persons control over the formulation, results, and uses of any research on disability which involves Independent Living Centres.

Types of Social Research on Disability

It is more likely that an Independent Living Centre will be asked to participate in social science research on disability, than being asked to participate in medical research. Therefore, issues involved with medical research on disability will not be considered in this report.

There are many kinds of research in the social sciences. Some of the principal types are listed below in Figure 2. It should be noted that many researchers combine approaches, and that the list below is only one way to organize the various kinds of social science research. As well, most types of social science research can be quantitative and/or qualitative. The particular combination of methods used should be derived from the particular research questions being asked.

Figure 2 - Major Types of Social Science Research

Primarily Quantitative Research (mostly uses numbers as data)

Questionnaires/Surveys/Interviews for collection of statistics
Field Studies for collecting quantitative data
Evaluation Research
Correlational Research
Causal-Comparative Research
Experimental Research
Action Research

Primarily Qualitative Research (mostly uses description as data)

Historical Research
Ethnography/Naturalistic Observation
Ethnomethodology
Discourse Analysis
Symbolic Interactionism
Phenomenology
Grounded Theory
Social Policy Research
Ecological Studies
Evaluation Research
Case Study/Life History
Participatory/Collaborative Research

Issues for Research on Independent Living

There has not been a lot of research on Independent Living for persons with a disability. Examples include the program evaluation of the eleven Independent Living Centers in California, described by Stoddard in 1983. Four methods of data collection were used by Berkeley Planning Associates who carried out the study: "analysis of existing center and agency materials; client survey (by mail); site visits to each center; and interviews with community and state officials" (Stoddard, 1983, p. 275). Areas evaluated included the range of Independent Living services, a profile of the clients, patterns of service use, Independent Living outcomes, and costs associated with the Independent Living model.

In another example, Brooks (1983) describes a field research study of disabled consumers which used qualitative methods based on ethnographic observation techniques. Brooks states that "...it is likely that investigators will be able-bodied individuals" (p. 301). She then outlines some of the difficulties which can arise from this fact:

If they [the researchers] are not experienced, their reactions to disability may interfere with communication. Nervous investigators may behave awkwardly, fidget, stand too far away, or lose eye contact with disabled subjects. Such behaviours are typical of initial able-bodied to disabled person interactions...In the second place, field researchers must be prepared to observe or partake in activities that are stigmatized by society. Long-term observers of the severely disabled will learn about the daily business of managing catheters and leg bags, braces and respirators, spasticity and drooling, and through that learning they will become partly stigmatized themselves...Many researchers will find suspending everyday wisdom and entering the world of severely disabled individuals an uncomfortable experience, partly because they may feel parasitic knowing that they will report their observations to outsiders...A third consideration in IL field studies is the ambiguity of researcher-subject relationships. All observers are likely to experience some role conflict as they perform research in the context of personal relationships, but deciding whether to act as a person or a researcher can be markedly problematic when disabled subjects request aid from an observer. (p. 301-302)

This last comment is interesting because, in trying to maintain the classical posture of the "value-free, neutral scientist", a researcher may not act as any caring individual might normally act.

Other examples of collaboration between organizations of disabled people and non-disabled researchers include the making of a film by non-disabled consultants for an Independent Living organization (May and Hill, 1984) and projects recently described by Zarb (1992), which include studies commissioned by groups of disabled people, and other studies which had a framework of "user's perspectives" in their implementation. Zarb gives four critical questions for the "critical evaluation of research practice" (p. 128):

- (i) Who controls what the research will be about and how it will be carried out?
- (ii) How far have we come in involving disabled people in the research process?
- (iii) What opportunities exist for disabled people to criticise the research and influence future directions?
- (iv) What happens to the products of research? (p. 128)

As noted previously, much of the research on disability does nothing to increase disabled people's choice, flexibility and control in their own lives. This is because the basic assumptions of social and medical research are rooted in the assumptions of

professionalism, with the "expert" knowing what is best for others. One way of dealing with this problem is through a new approach known as participatory research.

Participatory Research as an Emancipatory Alternative

Participatory research is an emancipatory approach which has already been developed, although it has rarely been used with the participation of persons with a disability. It would seem to fit best with a model of Independent Living which is based on self-help, control of services, and advocacy/struggle against oppressive conditions or domination by others. Chesler (1991) comments that participatory research "is most consistent with self-help characteristics and ideology: highly participative membership, a professional leadership, localist and grass-roots orientation, and respect for experience-based knowledge" (p.757). In contrast, non-participatory action research would seem to fit best with the ideology of the consumer model of Independent Living.

Participatory research grew out of an educational method used in developing countries known as popular education, a liberating method of educating the poor. This method is a mix of ideas from Paulo Freire's efforts in adult literacy in Brazil, Catholic liberation theology, and the views of the neo-Marxist Antonio Gramsci (Latapí, 1988). Much of the literature on participatory research indicates that it has been mainly applied in the "Third World". The roots of participatory research are found in the work of Brazilian educator Paulo Freire, a priest who was exiled from Brazil for many years for his methods of teaching poor peasants how to read. Participatory research methods have been applied in a wide variety of settings in developing countries. Rahman (1978) reviews participatory research projects with persons classified as "rural poor" in Latin America, South Asia and Africa. Almeida et al. (1983) describes a project of participatory research in the mountain state of Puebla, Mexico where a group of well-educated urbanites went to live permanently in a village of native people. Here they trained the villagers in participatory research methods, resulting in the development of local leadership and many self-help projects by the members of the village. Kirkpatrick (1990) outlines a participatory nursing research program in the Dominican Republic involving mothers and their children. Hall (1984) lists 14 participatory research projects in 7 countries which range from a village socio-economic analysis in Kenya to the development of women's clubs in India.

Hall (1984) defines participatory research as "a three pronged activity which integrates a research process (social investigation) with educational work through an action designed to deal with specific problems" (p. 290). Participatory research, says Hall, arose from several kinds of activities:

- a. The engagement of many adult educators in the everyday lives of the people with whom they work.
- b. A critique of the role and methods of the most commonly used forms of research.

c. An interest in educational forms which strengthened social movements and empowered people.

d. An interest in contributing to an alternative base of knowledge which has its focus on the transformation of society. (p. 291)

Participatory research has the following principles:

1. Research should involve people in the entire process beginning with identification of the issues, through discussion of how to get the information, to analysis and use of results within the context of action.

2. Research should result in some direct and positive benefits for those communities and people involved.

3. Research is a process of systematic creation of knowledge which may or may not involve people who have been professionally trained as researchers.

4. Knowledge is deepened, enriched, and made more socially usable when it is produced collectively.

5. Research involves a combination of methods designed to facilitate social, cooperative, or collective production of knowledge.

6. Research, learning, and knowledge production are often aspects of the same intellectual processes in the context of action. (Hall, 1984, p. 291-292)

Participatory research is a radical approach to social research, and an emancipatory interest is inherent in its philosophical assumptions. It is based on a conflict model whereby people who are controlled by others must learn to take action themselves, using the same tools and information which is available to those who now control them. In contrast, *action research* is not usually very radical in its approach, using both qualitative and quantitative methods to solve local problems, *without the involvement of disabled persons in the design, implementation or analysis of the research*. The differences in the assumptions between action research and participatory research are discussed by Brown and Tandon (1983), and summarized in Figures 3 and 4.

Figure 3 - Values and Ideologies in Action Research and Participatory Research

| | ACTION RESEARCH | PARTICIPATORY RESEARCH |
|----------|---|--|
| Values | Useful knowledge Developmental Change | Useful knowledge Developmental Change |
| Ideology | Individual/Group Analysis Consensus Social Theory Efficiency/growth problems are central | Societal Analysis Conflict Social Theory Equity/self-reliance/oppression problems are central |

Adapted from Brown and Tandon (1983), p. 283.

Figure 3 notes the differences in values and ideology between action research and participatory research. While both methods share the same values of producing useful knowledge and promoting developmental change, they differ in their ideologies. Action research is based on individual or group situations within the society, while participatory research is based on an analysis of society as a whole. Action research is to solve problems which will then make the world run smoother for everyone (consensus social theory), while participatory research is based on a conflict model of social relations in which one group must struggle to win their rights from another. Finally, action research is usually about solving problems to make the systems in place run more smoothly or to help them grow; participatory research is concerned with equality, self-reliance and freedom from the oppressive control of others, rather than focusing on the needs of the system.

Figure 4 indicates the main operational differences between action research and participatory research, as well as the balance of interests and authority involved in each model. While both models of research involve researchers with expertise and client groups, in participatory research established authorities and third party funders (usually social change agencies) also become involved. This is because participatory research results are likely to confront the power structure and to work towards changing fundamental relationships and ways of understanding the situation. In action research, there is often the solving of a local problem without any impact outside the setting involved. Second, in participatory research, the client groups are much more involved in all stages of the research, and are the principal beneficiaries of the results of the research. In action research, the client group works in collaboration with the system, and the end result is used to improve the running of the system.

According to Brown and Tandon, participatory research involves exploited or oppressed groups, who define the central problem of the research as uncovering and opposing oppression. "This perspective has at least three implications: (1) participatory research clients will define problems differently from dominant groups, (2) authority and resources will be controlled largely by other interest groups, and (3) dominant interest

groups can be expected to resist or attack problem definitions that threaten their positions" (Brown and Tandon, 1983, p. 284).

Figure 4 - Political Economies of Action Research and Participatory Research

| | ACTION RESEARCH | PARTICIPATORY RESEARCH |
|---------------------------------|---|--|
| Actors | <p>Researchers</p> <p>Client Systems</p> | <p>Researchers</p> <p>Client Groups</p> <p>Established Authorities</p> <p>Third Party Funders</p> |
| Resources and Authority | <p>Researchers Provide research expertise</p> <p>Client Systems Provide sanction insights information</p> | <p>Researchers Provide research expertise political awareness</p> <p>Client Groups Provide information energy insights</p> <p>Established Authorities Provide sanction power funds and rewards</p> <p>Third-Party Funders Provide funds protection</p> |
| <u>Impacts on Phases</u> | | |
| 1. Problem Definition | <p>Shared by researchers and client system</p> <p>Benefits provided to the whole system</p> <p>Resources and sanction from system leaders</p> | <p>Controlled by client group</p> <p>Benefits provided to client group</p> <p>Resources received from clients or extracted from the system</p> |
| 2. Data Collection and Analysis | <p>Collaborative with the whole system</p> <p>Iteration to system-wide shared diagnosis</p> | <p>Collaborative with clients; adversarial with authorities</p> <p>Iteration to educate and mobilize client groups</p> |
| 3. Uses of results | <p>Systemic consensus on goals of intervention</p> <p>Problem solving with systemic benefits</p> | <p>Client consensus on goals of intervention</p> <p>Negotiation to improve client situation</p> |

From Brown and Tandon (1983), p. 288.

Participatory research has also been used to solve problems within the workplace but only by changing the traditional relations between management and labour; Whyte, Greenwood and Lazes (1989) describe such a change at the Xerox Corporation in the United States. As well, participatory research has been used as an approach to organizing poor people in Great Britain to improve their standard of living (Holman, 1987), and in Canada for community organizing and development (Whitmore and Kerans, 1988). Ralph (1988) reviews a number of participatory research projects which involved exploited

women, including a study in Great Britain which was suggested and managed by a organization of prostitutes. To quote Le Boterf (1983) participatory research "aims to serve the most underprivileged groups and social classes. It also constitutes an educational process" (p. 167).

Participatory Research Methods

Participatory research methods can serve many purposes, and can include a diversity of research approaches depending on the problems and issues identified by the participants. Participatory research may be used to:

- promote the production of *collective knowledge*: the investigation and presentation of a social reality by the group(s) living it, with a *group ownership* of the information;
- promote *collective analysis*: the ordering of information in ways useful to the group in examining their reality;
- promote *critical analysis* by groups and individuals: using the ordered information to determine the root causes of problems and issues apparent in the constituency, with a view to finding solutions to them;
- promote the building of relationships between personal and structural problems as a part of the collective problem solving process;
- link reflection and evaluation with action, taking time to ask who, what, why, where, when? (Participatory Research Network, 1982)

These methods may be used at any point in the three processes of participatory research - investigation, analysis and/or action (Ibid.). Most participatory research is a group effort, and community building among the participants is one the objective of participatory research. Group discussions, public meetings, community seminars, open-ended surveys, the forming of research teams, fact-finding tours, collective production of audio-visual materials, popular theatre, group mapping and drawing exercises, group writing, and educational camps, can all be part of the process.

The steps in working through a participatory research process are given in Figure 5 below. Figure 6 is a list of critical issues and questions in the process of working in the participatory research model. While the process may start with an experienced facilitator, control of the process rests with the participants involved, and leadership quickly emerges from the groups themselves. In the same way, an action plan becomes the responsibility of the participants, rather than the usual reliance on professional "help" to always solve problems faced by the community.

Figure 5 - The Process of Participatory Research

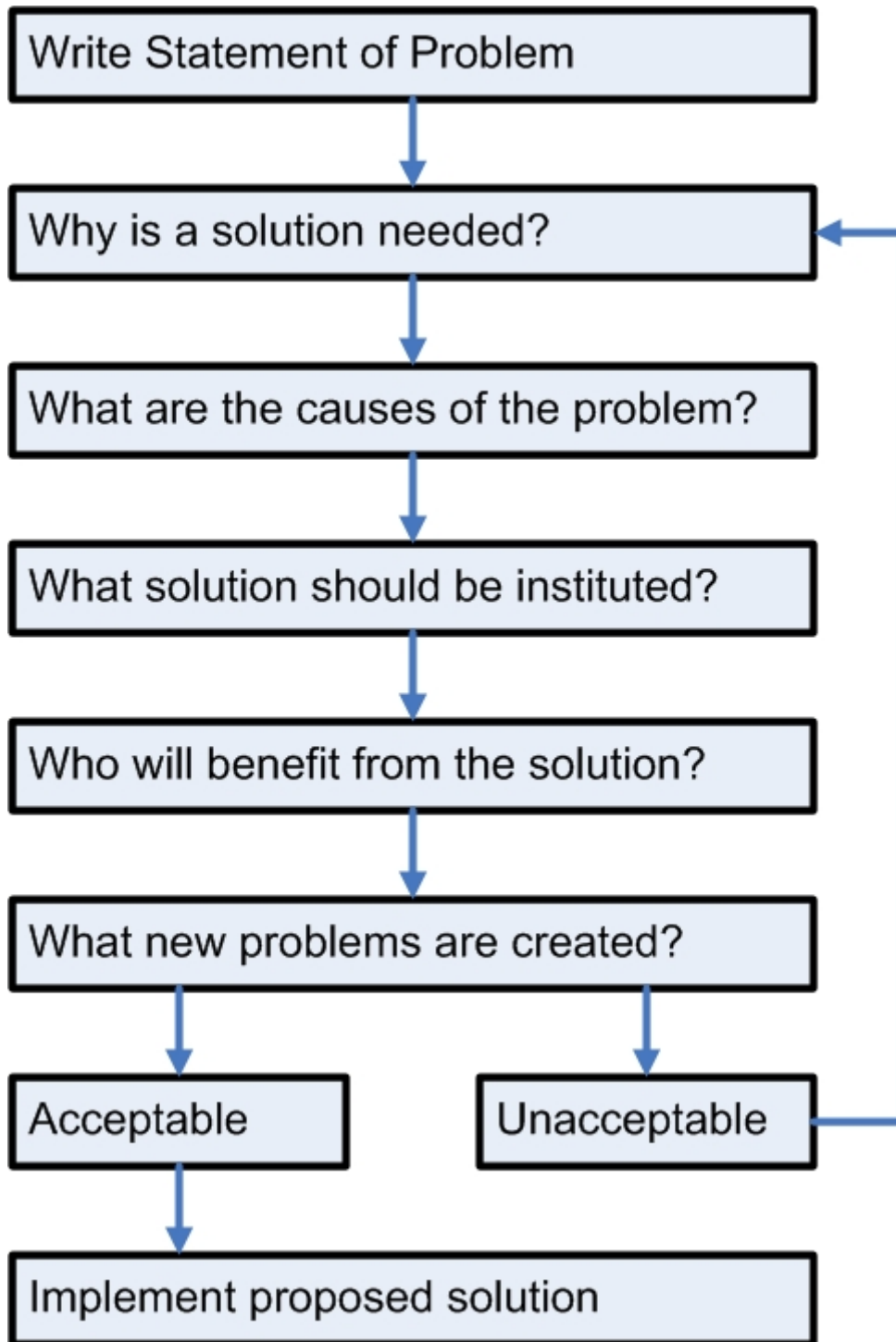


Figure 6 - Questions and Issues in Participatory Research

Initiation and Control

Who initiates?
Who defines the problem?
Who pays?

Critical Content

What is studied?
Why?
By whom?

Collective Analysis

How is information gathered?
By whom?
How is data analysed?
By whom?

Learning and Skills Developed

What is learned?
Who develops what skills?
What are the products and by-products?

Uses for Action

How are the results disseminated?
Who uses them?
How are they used?
Who benefits?

From:

Participatory Research Network (1982) *Participatory Research: an introduction*. p. 42

In summary, we can link the various types of research discussed above with a particular model of social science research. This is presented in Figure 7 below. As the chart indicates, participatory research, while not the only type of research which Independent Living Centres can support, is a model which fits very well with the aims, methods and philosophy of the Independent Living movement in Canada.

Figure 7 - Relationship between IL models and types of research

| <u>IL MODEL</u> | <u>RESEARCH MODEL</u> | <u>POINTS IN COMMON</u> |
|----------------------|---|---|
| Professional model | Empirical, large scale, group data | Control by Professionals Disabled person is object of study |
| Market Economy model | Action research, empirical, small scale studies | Collaboration between consumers and "expert" service provider |
| Community model | Participatory research, qualitative | Control by participants, community development is part of the process |

PART 5

Research Guidelines for Independent Living Centres

In the end, the staff of an Independent Living Centre may be faced with a number of requests to either participate in or endorse a program of research, or to evaluate and use the results of research. Based on the above discussion, a general principle can be articulated:

All research on disability should significantly involve persons with disability in the setting of the research agenda, in the formulation of research questions, and in the interpretation and use of the results.

It is recommended that when research proposals are received by organizations of disabled persons they be reviewed by a consumer-controlled research committee. Such a committee should include a majority of persons with a disability, and at least one person who has graduate training in social science research methods.

One reason that Independent Living Centres should participate in the process of research is simply that research on disability will continue, whether persons with a disability assert themselves or not. It is better for disabled consumers to get involved and take some control over the process, than to leave research to the mainly non-disabled academic and professional community. The results of research are constantly being used to formulate or to justify social policies which will affect the lives of persons with a disability. Persons with a disability or Independent Living Centres who are asked to participate in academic/profession research should be aware of the problem of tokenism, whereby an Independent Living Centre or a disabled consumer is asked to endorse and therefore legitimize research programs over which they have little real control. In particular, disabled consumers should be aware of the trend to form committees of "consumers" or "stakeholders" (in research proposals these terms can mean persons with a disability, but may mean parents, relatives, and/or professionals), to approve plans and review results after the research program is well underway. While some modifications may be made based on this level of participation, the danger is that the broad parameters of the project will not be changed because of the arrangements which have been already put into place.

To Participate or Not to Participate - That is the Question!

The process of academic research has a long history, with its sets of procedures, standards, and traditions. Much of the process of research is designed to give results which are both valid and reliable. Yet these same procedures may mask the relations of power, and the possible abuses or misuses of research which are possible if persons with a disability are sources of data in an academic research program.

Some aspects of the research process are so basic, that they are almost taken for granted by the academic community. For example, it is standard practice to give a detailed written proposal to organizations from which you are asking cooperation as a researcher. As well, all research involving human subjects, from interviews and questionnaires to complex experimental research, is required to be submitted to an ethics review committee before potential subjects are approached. Every participant in research who is a source of data should be asked for written informed consent, except for persons under 18, where permission of the parents is required. Part of the process of asking for consent is giving the potential participant sufficient information about the research to make an informed decision. For a sample consent form, see APPENDIX B.

Beyond these basics, a research committee should examine the goals, methods, and uses of the research, as well as the "track record" of the researcher(s). In addition, in keeping with the philosophy of Independent Living, the issue of consumer control and input is important to look at; the actual amount of control needed will vary depending on the nature and importance of the research. Based on the discussion in this paper, a set of questions for a research committee to use in evaluating research proposals is presented in APPENDIX A. These, of course, may be modified or supplemented as a research committee sees fit, but it is hoped that they will be useful to Independent Living Centres or disabled consumers in making a decision on whether or not to participate in research on disability.

APPENDIX A - Suggested Steps in Evaluating a Research Proposal

1. Is there a written proposal for this research? If yes, continue; if no → Reject
2. Has the proposal passed an ethics review? If yes, continue; if no → Reject
3. Is there a satisfactory consent form attached to the proposal? If yes, continue; if no → Reject
4. Have persons with a disability been genuinely consulted in the formulation of this research proposal? If yes, continue; if no → Reject
5. Is the level of control by disabled consumers satisfactory for this type of research? If yes, continue; if no → Reject
6. Has the researcher provided a sample of his or her previous writing on disability, or as an alternative, is willing to meet the research committee to discuss his or her views on disability? If yes, continue; if no → Reject
7. Do the results of the review of previous writing or an interview indicate that the researcher is someone the committee feels is in solidarity with the goals of Independent Living for persons with a disability? If yes, continue; if no → Reject
8. Are the goals of the research clearly stated? If yes, continue; if no → Reject
9. Are the goals of the research likely to benefit persons with a disability? If yes, continue; if no → Reject
10. Does the research support a community based, consumer controlled model of Independent Living? If yes, continue; if no → Reject
11. Are the demands on each subject's time reasonable and voluntary, or is there a significant direct benefit to each subject, or is there payment for each subject's time? (A "yes" to one of these conditions is needed). If yes, continue; if no → Reject
12. Does this research treat persons with a disability as individuals without resorting to group stereo-types or negative images (e.g., an emphasis on functional limitations of persons with a disability)? If yes, continue; if no → Reject
13. Does the researcher show an understanding of the experience of being disabled from a consumer's point of view? If yes, continue; if no → Reject
14. In this research, are the assumptions about disability and persons with a disability acceptable? If yes, continue; if no → Reject
15. Are the proposed research methods likely to answer the questions raised by the researcher? If yes, continue; if no → Reject

16. Will the subjects of the research, and other persons with disability, be able to receive the results in a form that they can understand? If yes, continue; if no → Reject

17. Will the results of the research be useful to the subjects or to other persons with a disability? If yes, continue; if no → Reject

18. Will persons with a disability be involved at some stage of carrying out the study, and/or interpreting the results? If yes, continue; if no → Reject

19. Are all of the above conditions fully met in this research proposal? If yes, → Accept proposal

APPENDIX B - Sample Consent Form for Research Participant

Consent Form

I understand that my participation in this research project is voluntary and that I may withdraw from the study at any time without penalty. I also understand that personal data will be coded to insure confidentiality, and that identifying names and descriptions of individuals who participated in the study will be excluded in any report on this research, unless I give specific written permission to be identified with a particular quotation. In this case I will be shown the quotation, its context, and the description of me as it will appear in the report, before I am asked to give my written permission for the use of my words.

As a participant in this study, I will spend approximately __ hours being interviewed/participating in a discussion group/completing the attached questionnaire. Although participation involves no future obligation, I understand that I may be contacted for future followup interviews involving identical procedures and will have the opportunity to participate in additional research if I so wish. I understand that I can choose to not answer any individual question given to me by the researchers, or, where any recording (written, audiotape, videotape) is used to store the proceedings of a discussion, I can require that any portion of my participation be not recorded or excluded from the final data.

I will not be paid for my participation in this study/I will be paid \$_____/ hour for my participation in this study. I understand that I will receive a summary of the results of the study before _____ (date).

I understand that the purpose of this study is to _____ (insert brief statement of purpose of the research). The procedures of the study have been explained to me by the researchers and I have a satisfactory understanding of them. Any further questions about the research and my rights as a participant will be answered by contacting the research director, _____ (name, address, phone number). I understand that this project has been reviewed and approved by the ethics review committee at _____ (institution) as adequately safeguarding subjects' privacy, welfare, civil liberties, and rights. I may address questions and complaints to the Chair, Ethics Review Committee - _____(name, address, phone number).

I have read the material above and any questions I asked have been answered to my satisfaction. I agree to participate in this research activity, realizing that I may withdraw without prejudice at any time. I understand that I have given informed consent and the opportunity to seek clarification.

_____ Signature of Subject

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